CODE STATUS?

CRITICALLY EVALUATING CANADIAN 'DO NOT ATTEMPT RESUSCITATION' (DNAR) ORDERS

by

Rachel E. Banks

Submitted in partial fulfillment of the requirements
for the degree of Master of Arts

at
Dalhousie University
Halifax, Nova Scotia
December 2021

TABLE OF CONTENTS

ABSTRACT

In this project, I explore and critically evaluate the theory, practical value, and accessibility of 'do-not-attempt-resuscitation' (DNAR) orders as they exist in the Canadian healthcare context. I first explain how DNAR orders developed in response to the standardization of in-hospital resuscitation practices. I begin my analysis by examining the bioethical concepts of presumed consent and medical futility, which frame the modern CPR/DNAR debate. I demonstrate how typical applications of these concepts may lead to the compromising of prevalent principles of healthcare ethics they are intended to uphold. I then introduce and describe the problem of overintervention in end-of-life care that is facilitated by default systems of presumed consent to CPR and is challenged by patients' and substitute decision-makers' DNAR orders. Finally, I describe and suggest solutions for potential barriers to DNAR accessibility that limit Canadian patients' ability to refuse and prevent overintervention in their end-of-life care.

ACKNOWLEDGMENTS

I am grateful to my supervisor, Dr. Kirstin Borgerson, for encouraging me and my ideas throughout this project (and several other projects). I have learned so much from you since my first year of university and have always been inspired by your breadth of knowledge, your expertise in diverse areas, and your patient and supportive teaching. I am also grateful to my readers, Dr. Letitia Meynell and Dr. Tyler Hildebrand, for their generous comments and attention to detail. Thank you for holding high expectations of my work and for guiding me to meet them.

I thank the BK family for keeping me sane and silly while I worked on this project. It has been such a privilege to work with dear friends who teach me so much. I also thank my family for championing me and taking me seriously as a scholar since the day I learned to read. Mum, Scarlett, Jonah, Joe, and Nana—if I do good and meaningful things in this life, know that it is because of you.

Lastly, I thank my chosen family who have listened to me, challenged me, cheered for me, and cried with me over the past five years. I am forever grateful to be a woman held up by (mostly) women and it is my greatest honour to make you all proud. Caleigh, Christina, Qendresa, Jenna, Kiersten, Noah, Jayla, Katie, Chiara, Kerry, Danae, Sully, and Thalia—you are gifts to me, and you have all my love.

My thesis is dedicated to my mum, Michelle, who is the best of all of us. Thank you for always paying attention.

CHAPTER 1: INTRODUCTION

> Cardiopulmonary resuscitation is indicated for the patient who, at the time of cardiopulmonary arrest, is not in the terminal stage of an incurable disease. Resuscitative measures on terminal patients will, at best, return them to the dying state. The physician should concentrate on resuscitating patients who were in good health preceding arrest, and who are likely to resume a normal existence. (Jude & Elam, 1965, p. 6)

I. Thesis Outline

In the modern healthcare setting, cardiopulmonary resuscitation (CPR) is such an established medical practice that the question of its ethical use is not whether it should be attempted, but whether it should be withheld. The medical acts of withholding or refusing resuscitation measures via orders known collectively as 'do not attempt resuscitation' (DNAR) are currently at the center of debates in healthcare ethics about issues of informed consent, quality of life, and harm reduction near death. These orders are controversial because they seem to conflict with traditional bioethical principles of beneficence, non-maleficence, justice, and respect for autonomy (Beauchamp & Childress, 2009). My thesis is devoted to exploring this apparent conflict in order to better understand what we are getting right with DNAR orders and what we are getting wrong with default resuscitation practices. My analysis is focused broadly on the ethical, social, and epistemic issues raised by DNAR in the Canadian healthcare context.

The main objectives of my thesis are, first, to provide an overview of current resuscitation practices and related policies in various Canadian jurisdictions; second, to

critically analyse these practices and policies in order to determine whether they successfully uphold prevalent principles of healthcare ethics; and third, to identify and draw some conclusions about potential barriers to effective uptake of DNAR orders as an end-of-life care option amongst Canadian patients. I argue that DNAR is not a live and meaningful care option when there is insufficient awareness and understanding amongst the lay public about the realities of the dying process, cardiopulmonary arrest, and resuscitation outcomes, and/or when patients cannot easily select and enact a DNAR order due to structural barriers in the clinical context. When DNAR is not a live and meaningful care option, the principles of beneficence, non-maleficence, justice, and respect for autonomy are compromised to varying degrees in end-of-life care for terminally ill patients.

In the remainder of the introductory chapter, I situate myself within the scope of the project by explaining my personal motivations for investigating the theory, practical value, and accessibility of DNAR orders. To situate the reader, I then provide an overview of some terminology and of the general infrastructure for DNAR orders as it exists in various Canadian healthcare systems. I conclude the introduction with a brief history of DNAR orders and how they developed in response to the standardization of in-hospital resuscitation practices.

In Chapter 2, I identify and explore in some detail two key concepts that are at work in current debates and decision-making about DNAR: presumed consent and medical futility. Throughout the chapter, I demonstrate how typical applications of these concepts produce tensions among several of Beauchamp and Childress' four principles of bioethics (2009), and I explain how applications of each concept are justified in practice

despite their potential to compromise one or several of these principles. In the first section, I explore the use of presumed consent to cardiopulmonary resuscitation (CPR) in the in-hospital and out-of-hospital settings. I draw from Bishop et al.'s (2010) critical discussion of current resuscitation practices to make helpful distinctions between the circumstances of cardiopulmonary arrest for patients hospitalized with serious illness and for individuals in a public setting. I argue that, on the whole, presumed consent is not a sufficient replacement for meaningful, informed consent to a non-neutral medical intervention like CPR, but that there are circumstantial constraints in the out-of-hospital setting which leave intervening bystanders with few other options for helping the individual in cardiopulmonary arrest. I elaborate on the circumstantial differences between the in-hospital and public settings to demonstrate where factors that ground the use of presumed consent may or may not be in force.

In the second section of Chapter 2, I critically engage with the concept of medical futility, which is used to support decisions to withhold resuscitation methods from patients in cardiopulmonary arrest. I explore how inconsistent appeals to this vague and ill-defined concept in the clinical setting may lead to the compromising of bioethical principles of beneficence, non-maleficence, and justice. Finally, I provide an overview of some arguments that support the use of the medical futility concept in practice despite the concept's limitations. My objective in Chapter 2 is to lay the theoretical groundwork for evaluating the practical value and accessibility of the DNAR order as an end-of-life care option which can uphold and meet the standards of prevalent principles of biomedical ethics.

In Chapter 3, I shift from theory to practice in order to assess what makes DNAR orders practically valuable for patients and what may prevent Canadian patients from accessing them. I first explain the problem of overintervention in end-of-life care, which motivates the need for DNAR orders in order to resist clinical norms of overintervention. I then identify potential epistemic and structural barriers that may limit the extent to which Canadian patients can access DNAR orders, and I argue that these barriers collectively jeopardize fundamental healthcare goals. Finally, I provide an overview of some suggestions for minimizing the effects of these barriers and enhancing DNAR accessibility in order to reduce and prevent overintervention in end-of-life care.

II. Personal Connections to the Project

My interest in the topics of DNAR orders and resuscitation practices is twofold. First, having been raised by paramedics, I was introduced to these topics and their importance early on as my parents shared some of their work experiences with me. At a young age I learned that death does not always occur suddenly, unexpectedly, or tragically; some deaths take weeks or months, are anticipated long before they occur, or offer relief to the dying and their families. Paramedics have a unique but difficult position as witnesses to both the sudden and the prolonged types of death. My father in particular has witnessed plenty of both types of death and, as a result, has insights about whether medical intervention to prevent death is appropriate, beneficial, or harmful.

He has also shared that, in his experience, many patients who are seriously or fatally ill are not aware of the healthcare options available to them at the end of life. When patients are aware of the options, they often have not had definitive conversations with their families or healthcare teams about which care measures they want enacted if

they lose decision-making capacity, consciousness, or cardiopulmonary function. As a result, many fatally ill patients get resuscitated from clinical death once or even multiple times, sometimes against their wishes (paramedics are required by law to initiate CPR unless the patient has visible proof of a documented DNAR). Some patients are defibrillated or intubated to no avail, and others are resuscitated to minimal function and sped to the hospital only to die days later while unconscious and supported by artificial ventilation. As my father sees it, many of these patients have been failed by a healthcare system that encourages intervention but does not sufficiently encourage discussion or decision-making about intervention before it becomes urgently necessary. My father and I have had many conversations about these topics over the years, which have formed my foundational understanding about resuscitation practices, overintervention, DNAR orders, and the ethical significance of these issues.

Second, and based on this foundational understanding as well as my own experiences witnessing this side of healthcare, I have become interested in the discourse and literature surrounding harm reduction and prevention of suffering in end-of-life care. There is growing consensus that the medical battle against the biological inevitability of death can result in tremendous harm to patients, and there is increasing attention to healthcare options which provide patients and families with greater control over the interventions a patient receives as they approach death. As an advocate for maximizing patient choice in healthcare generally, I am particularly interested in those healthcare options which provide patients with meaningful choice about when and how they may die (e.g. hospice, palliative care, MAiD, and DNAR orders). I believe these are some of the most important choices we can make and, consequently, that access to such healthcare

options is an important matter of healthcare justice. DNAR orders are one healthcare option by which one can withdraw and seek quietude in death[1] amidst medical and social environments that often miscast such efforts as 'giving up'.

In this project, I explore resuscitation practices and DNAR orders in Canada broadly from my perspective as an adult Canadian who is familiar with these issues mainly through my proximity to emergency healthcare providers. I hope that this project provides important reminders of our biological limits, the limits of medicine, and the possibility of welfare in dying.

III. Providing Context

In most Canadian jurisdictions, older or seriously ill adults are encouraged to engage in advance care planning that can include designating substitute decision-maker (SDMs), communicating preferences for hospitalization and types of care, and selecting pre-emptively from options for end-of-life care[2]. These decisions are typically documented as advance care orders (e.g. Alberta's Goals of Care orders), or some such form of documentation that is recognized within a particular province. End-of-life care options in Canada currently include palliative care, medical assistance in dying (MAiD), refusal or withdrawal of treatment, and DNAR orders in various forms (Health Services Canada, 2017). These options are available to most patients or their SDM, with some

[1] I am loosely referencing Freud's theory of the death drive in *Beyond the Pleasure Principle* (1920) here.
[2] In the Ontario healthcare context, SDMs are legally entitled to make decisions on behalf of a patient only when the patient is deemed incompetent or medically incapable of making decisions of their own. A SDM's authority is strictly limited by the patient's capacity; for example, a SDM does not have continuing authority to make decisions on behalf of the patient when the patient becomes capable after a temporary period of incapacity (Ontario Health Care Consent Act, 1996). These stipulations are largely consistent between provinces and territories in Canada.

stipulations around patient age, degree of competence, health condition, and proximity to death.

In this project, I focus specifically on resuscitation orders, commonly known as 'do not resuscitate' (DNR), 'do not attempt resuscitation' (DNAR), 'no cardiopulmonary resuscitation' (No-CPR), or 'allow natural death' (AND) orders, which fall within the category of end-of-life care options and advance care planning more generally. These abbreviated designations can be used somewhat interchangeably, though 'DNR' has historically been used as an all-encompassing term that includes both the actual order for healthcare providers and the process and policies for withholding resuscitation measures (Puri, 2006). Since the mid 2000s, initiatives to improve communication around end-of-life care have encouraged moving away from obsolete 'DNR' terminology to clearer 'DNAR' or 'No-CPR' terminology in order to minimize the implication that resuscitation is likely to be successful and to foster better emotional preparedness for understanding what the order means (Breault, 2011; Henry, 2016). However, both 'DNR' and 'DNAR' may produce misperceptions that less care will be provided, if they are interpreted by patients or families as 'do not treat' orders. For this reason, some commentaries have recommended that 'AND' is the better terminology since it does not imply that action is being withheld but rather gestures in positive language towards the natural progression of death without clinician interference (Breault, 2011). The language used to discuss end-of-life care measures with patients and the general public is important since high stress and emotions around the topic make misunderstandings or misimpressions more likely at times when clear medical decision-making is crucial (Henry, 2016). Throughout this

thesis, I use 'DNAR' terminology per recommendations to clearly indicate that resuscitation attempts are precisely *attempts*.

A DNAR order in its simplest form designates that no attempts be made to restore heart function or breathing in a patient experiencing cardiopulmonary arrest. This includes the withholding of all methods of cardiopulmonary resuscitation (CPR), such as chest compressions, defibrillation, intubation, or other possible interventions (e.g. chemical assists, cardiac massage, etc.). A DNAR order does not affect any treatment besides emergency resuscitative methods; an individual with a DNAR order can continue to receive antibiotics and other required medications, chemotherapy, dialysis, or other appropriate treatments needed to sustain life. Typically, a patient's DNAR order is indicated to their healthcare team via medical records, and is made known to the patient's family members or friends who can relay the order to first-responders if the patient experiences cardiopulmonary arrest outside of a clinical setting. A DNAR order can be cancelled or amended at any time by the patient, their SDM, or an attending clinician.

Having laid down some terminology and technical details around the DNAR order, I will now outline a brief history of its development since it was introduced to healthcare over a half century ago, followed by an overview of different provincial regulations around DNAR orders. The intentional withholding of resuscitative intervention first became a live option in response to the widespread uptake of CPR as routine in-hospital care in the 1960s in the USA and in Canada (Bishop et al., 2010). After CPR by closed-chest cardiac massage was established as a relatively simple but effective protocol for resuscitating patients in cardiac or pulmonary arrest, it quickly became a new standard of care for all hospitalized patients (Bishop et al., 2010).

Enthusiastic reception of CPR extended beyond the hospital setting, as the general public were encouraged to become competent in performing CPR as part of First Aid training and, more recently, automatic external defibrillators (AEDs) have become more widely accessible and available in public spaces (d'Amours et al., 2020). By the early 1970s, guiding principles and medical parameters indicating whether resuscitative efforts were appropriate began to emerge as it became clear that invasive resuscitative intervention was not universally beneficial nor consistently successful (Bishop et al., 2010). The limited usefulness of CPR challenged the growing technological optimism in the medical community and revealed practical and ethical needs for more nuanced decision-making regarding interventions for dying patients.

Formal orders not to resuscitate thus developed as early as 1976 as a rejection of CPR, and more selective criteria for appropriateness of CPR were suggested (Burns et al., 2003; Bishop et al., 2010). As indicated in the opening quotation of this thesis, only patients "who are in good health preceding arrest, and who are likely to resume a normal existence" were initially seen as appropriate recipients of resuscitation attempts (Jude & Elam, 1965, p. 4). These criteria have since become more nuanced and complex, as I discuss in more detail in the next chapter. By the 1980s, patient rights advocates had contributed to the CPR/DNAR debate and orders not to resuscitate were aligned with growing concerns about respect for patient autonomy, in opposition to paternalistic physician decision-making in the context of end-of-life care (Bishop et al., 2010). In the years since, DNAR orders have become deeply embedded in the values-driven, patient-centred healthcare movement as part of the continuum of end-of-life care options. It is widely recognized that individuals have the right to refuse potentially successful

resuscitation measures, as part of their broader right to refuse medical treatment and intervention, and the DNAR orders has become a means for upholding this patient right (Burns et al., 2003). Since DNAR orders are understood to protect patient rights, access to DNAR orders and other end-of-life care options is also a matter of healthcare justice.

On the other hand, some oppose DNAR on the grounds that these orders "violate professional ethics and represent a dramatic example of withholding of simple technology that mandates use" (Cotler, 2000, p. 625). More specifically, DNAR orders are sometimes interpreted as violating or compromising the principles of beneficence and non-maleficence, or what are seen as professional obligations to promote health and prevent harm in healthcare, if these are taken to include the extension of life and the prevention of death. I elaborate on the tension between the principles of beneficence and non-maleficence in the CPR/DNAR debate in Chapter 2. This debate continues to draw significant academic and media attention today, and CPR/DNAR conflicts in medical institutions frequently prompt judicial and regulatory responses in various nations.[3]

In most Canadian hospitals today, if a patient with DNAR status stops breathing or loses heart function, medical staff are instructed to forego resuscitation attempts and provide comfort care where appropriate. DNAR status can be nuanced in various ways to indicate particular levels of desired intervention, depending on province-specific or institution-specific regulations of end-of-life care. In Ontario for example, a Level Five (Full Resuscitation) code status can indicate that a patient will receive "all medically appropriate life sustaining measures" in the event of cardiopulmonary arrest, while a Level One (End of Life Care) code status can indicate that the patient will receive

[3] See as examples: *Tracey vs Cambridge University Hospital NHS FT* case in the UK (2015); *Wawrzyniak v. Livingstone* case in Ontario, Canada (2019).

"comfort measures only", such as pain-relieving or sedative treatments, but CPR, ventilation, and any aggressive medical care aimed at prolonging life will not be initiated (Thunder Bay Regional Health Sciences Center, 2018). In Nova Scotia, as of 2021, there is a 'Do Not Resuscitate Form' provided by the Nova Scotia Department of Health which can be accessed online, printed, and filled out in the presence of a witness. These DNR forms can be copied and added to personal care orders and medical records, or shown to first-responders attending a 9-1-1 call for cardiac or respiratory arrest, in which case the signed DNR form is the only legally binding instruction (outside of a hospital) to withhold resuscitation attempts. The Nova Scotia DNR form stipulates only that "no medical treatment will be started or continued" if the individual's heart stops beating or if they stop breathing.

As is true of most healthcare policies in Canada, policies surrounding DNAR orders differ between provincial healthcare systems, where some have implemented more nuanced frameworks than others. In 2014, Alberta Health Services implemented the Goals of Care orders as part of a province-wide advance care planning policy, which enable individuals to choose from detailed and multi-tiered options for resuscitative efforts, comfort care, and other medical interventions near the end of life (Alberta Health Services, 2021). In British Columbia, Medical Orders for Scope of Treatment (MOST) are available from regional health authorities to outline similar options, or a simpler 'No-CPR' medical order form provided by BC Emergency Health Services can be completed by a patient/SDM and a physician or nurse practitioner (HealthLink BC, 2019). Though Canada's health-related laws allow DNAR orders under the umbrella of end-of-life care options, there are currently no resuscitation orders that are standardized across Canada,

and development and implementation of DNAR orders are left to provincial health authorities.

There are also provincial differences in the legal discourse and administration around DNAR orders. Typically, patients or their SDMs can request a DNAR order after discussions with healthcare professionals regarding their values, preferences for care, and perception of quality of life (CMPA, 2021). If a patient is not able to give consent and they do not have a SDM, assigning a DNAR order falls to the discretion of the attending physician. In these cases, physicians' unilateral decisions to assign DNAR status are often supported by consultation with the regulatory board or ethics committee of the hospital in which they work (CMPA, 2021). The Canadian Medical Protective Association, a non-profit association which offers medico-legal assistance and protection to practicing Canadian physicians, has provided guiding principles for physicians' DNAR decision-making, interpretation, and implementation, but there is otherwise no regulation or oversight of legal DNAR-related consent requirements at the federal level (CMPA, 2021). In particular, there is no federal law requiring informed consent from competent patients or their SDMs for physicians to withhold resuscitative treatment (i.e. to not act), and provincial laws remain unclear. Some provincial courts have decided that physicians may not withhold or withdraw treatment without consent, others have decided that they may, and several provincial courts have not yet made decisions or have no clear legal position on this issue (Dalhousie Health Law Institute, 2021).

To summarize what I have introduced so far, 'DNAR' captures a complex framework of medical directives, policies in healthcare, responses in legal discourse, and outcomes for patients, which can vary across Canadian jurisdictions (i.e. provinces,

territories, or regions). In the following two chapters, I use 'DNAR orders' to refer to the medical directives as such, and I use terms like 'DNAR infrastructure', 'DNAR policies', and the like, to refer elements of the framework associated with DNAR orders.

CHAPTER 2: KEY BIOETHICAL CONCEPTS IN THE CPR/DNAR DEBATE

The central concern in the CPR/DNAR debate is that, specifically in the end-of-life care context, CPR can only rarely benefit the patient by temporarily restoring cardiac function (if at all), while it poses a significant risk of harming the patient by producing injury or trauma. However, failing to provide CPR for a patient in cardiopulmonary arrest most often results in their immediate and irreversible death. I explore in this chapter two key bioethical concepts, presumed consent and medical futility, which frame the CPR/DNAR debate around opposite goals of protecting physiological survival and minimizing harm by preventing injury or suffering from CPR. I focus on these concepts side-by-side because they motivate opposite actions towards resuscitative intervention, while each representing one side of a tension between prevailing healthcare goals of beneficence, non-maleficence, respect for autonomy, and justice (Beauchamp & Childress, 2009).

Presumed consent is used to sanction the provision of CPR in the absence of explicit and informed patient/SDM consent, on the basis that the possibility of benefit (i.e. successful resuscitation) outweighs the possibility of harm (i.e. injuries that CPR typically produces). At the same time, the medical futility concept is used to justify withholding CPR (and thus establishing or acting according to a DNAR order), on the basis that the possibility of benefit is either unattainable or so minimal that it does not outweigh the possibility of harm (i.e. from CPR or from prolonged survival). Clinicians' judgments of medical futility can, in many cases, be made without patient input and with a presumption of medical consensus. In this chapter I explain how the established understandings of presumed consent and medical futility that are operative in current

resuscitation practices actually lead to the compromising of fundamental healthcare principles they are intended to uphold. The main problem I identify, which motivates the project as a whole, is an inconsistent and perhaps at times even contradictory application of these two concepts in current resuscitation practices, given what is known empirically about CPR outcomes for cardiopulmonary arrest.

I. PRESUMED CONSENT TO CPR

A presumption of consent to bodily interference in a medical context is distinct from other types of presumptions. A presumption in law or science, for example, is one that holds until evidence or objection is provided to the contrary; it is a "provisional estimate of facts" based on some consistent, clearly-defined, and accepted state of things (Pierscionek, 2008). Because a presumption of this kind is provisional, it can be easily modified or retracted as new facts arrive (e.g. a confession of guilt or new empirical data). The presumption of consent to medical intervention, however, offers little to no possibility of refuting the presumption and abandoning any decisions made based on the presumption. When presumed consent is used in medical practice, the 'provisional estimate of facts' about the subject's preferences for intervention is no longer actually provisional—it is an estimate of facts upon which prompt and irreversible decisions for treatment are made. Presumed consent to CPR is thus better framed as an absence of specified refusal or objection to CPR, rather than an assumption of the subject's willingness to receive this intervention.

The decision-making process for attempting CPR is unique in medical practice, since few other clinical protocols operate under the automatic presumption of consent. In their 2010 article, Bishop et al. review the current American policies surrounding

CPR/DNAR and summarize the issue succinctly: "presumed consent to CPR has ensconced medical optimism in public policy and become the social norm" (Bishop et al., 2010, p. 61). This is also true in current Canadian practice, where patients maintain a "full code" status unless indicated otherwise by a DNAR order, meaning that attending healthcare professionals are required by law to initiate resuscitation attempts on all patients unless directed otherwise. "Full code" status means that all resuscitative measures are attempted, including those that may result in the need for long-term life-prolonging care requirements (e.g. intubation or emergency surgery). Importantly, this default full code system relies on the default use of presumed consent to CPR.

Per the prevailing model of practice in resuscitative intervention, "[default] CPR is predicated on the assumptions that life is sacred, to be maintained, and CPR will be successful; it is consistent with the belief that allowing someone to die is a harm." (Cotler, 2000, p. 623). Those attempting CPR for a person in cardiopulmonary arrest, whether they be medical professionals or laypeople, may act with the assumption that the arresting person would want to survive or, if not, that they *should* survive—due to religious or humanist or other moral convictions—and that failing to intervene and allowing them to die is thus a moral error. Since the individual in cardiopulmonary arrest cannot provide consent at that time, a forced choice is produced when the individual's preferences for care, their desired medical outcomes, and the potential consequences of unwanted resuscitation cannot be reviewed in the brief window available to help them. More specifically, the time constraints and the patient's incapacity prevent the possibilities of reaching adequate shared understanding and of amending or rescinding the decision to attempt resuscitative care, thereby preventing the possibility of choice for

the individual in cardiopulmonary arrest. By default, urgent time constraints and the threat of death are thought to justify the use of presumed consent because the requirements of informed and explicit consent cannot be met. Thus, default use of presumed consent to CPR necessarily assumes both an *emergency* and a *benefit to the patient* to justify foregoing the usual requirements of informed consent (Cotler, 2000). The assumed benefit is the prevention of death which is irreversible and therefore prioritized over other contingencies such as breached consent or possibility of injury.

However, medical professionals and academics contributing to the CPR/DNAR debate since the late 1990s have rightly raised the concern that we should not assume that resuscitation provides a benefit in all cases, nor that all medical emergencies override the requirement of informed and explicit consent for intervention (Ross, 1991; Cotler, 2000; Bishop et al., 2010). Additionally, the clinical circumstances in which the medical emergency occurs have an impact on the ethical obligations of those who are present to intervene, including their obligation to seek and acquire consent for intervention. For example, in out-of-hospital settings, there is a general assumption that non-professional bystanders are justified in attempting CPR without explicit consent on an acutely ill individual who is not breathing or has lost a pulse. This assumption is perhaps part of a broader social norm of non-consensual intervention in medical emergencies that is largely tacit and expected in Canadian society (such as the expectation that one would intervene to save a drowning person or to administer an Epipen to someone in anaphylactic shock). Though the clinical circumstances of in-hospital and out-of-hospital CPR intervention are importantly different, presumed consent to CPR is used in both settings if there are no SDMs available for the incapacitated patient.

Throughout the rest of this project I focus primarily on CPR/DNAR in the hospital context, but I explore the out-of-hospital context briefly in this chapter as a useful contrast case with which to draw out important nuances in the default use of presumed consent. I do not discuss the issue of default presumed consent for children and infants however, as this raises important but different consent-related concerns that are outside the scope of my analysis.

i. Default Presumed Consent on the Basis of Emergency

In this and the next subsection I describe and assess the model for default use of presumed consent to CPR intervention, which assumes both an emergency and a benefit to the patient. This model differs significantly from the prevailing model for informed consent in a hospital setting, which ensures that patients have a right to refuse potentially necessary or beneficial interventions even after having given general consent to hospitalization (Cotler, 2000). Typically, any non-routine interventions in a hospital setting (i.e. besides administering daily medications, changing wound dressings, and the like) are understood to require distinct discussions of the specific risks, benefits, potential outcomes, and alternatives with which the patient or their SDM can accept or refuse the physician's recommended course of action. Of course, this model of in-hospital informed consent is modified in true emergencies that arise acutely and unexpectedly, in which cases consent is either irrelevant or impossible to obtain. Some examples of such emergencies include the acute rupture of an appendix or cyst, apparent choking on a foreign object, or rapid blood loss from internal bleeding. Intervention for these unforeseen medical emergencies is required immediately to prevent death, and it is assumed that consent for any further intervention could be obtained once the patient has

been stabilized. An important factor for characterizing these sorts of medical emergencies *as* emergencies is their unpredictability within the context of the patient's status and prognosis.

Here I introduce Bishop et al.'s (2010) distinction between *proximal* and *distal* causes. Bishop et al. explain that most emergency medical protocols are aimed at addressing the symptoms and "proximal causes" of the medical crisis at hand (e.g. foreign object blocking airway, ruptured vessel causing blood loss) but do not necessarily impact the "distal causes" of the crisis and the patient's longer term prognosis (2010, p. 64). The distinction between proximal and distal causes of medical crisis is a matter of temporal urgency related to foreseeability. Proximal causes of medical crisis, like a foreign object blocking an airway or a ruptured blood vessel, are mostly unforeseeable and require immediate action to prevent death. Comparatively, distal causes of medical crisis (e.g. inhibited swallowing mechanisms from progressive muscle paralysis or weakened blood vessel walls from cardiovascular strain) can exist for much longer before medical action is urgently required and therefore produce medical crises that are foreseeable to at least some degree. This is particularly true if the distal causes are formally known and diagnosed, as is usually the case when an individual is hospitalized with serious illness. This distinction has important implications for the issue of consent because it determines what can rightly be classified as an 'emergency' medical crisis for the purposes of relying on presumed consent due to time constraints.

If we carefully consider the circumstances under which in-hospital cardiopulmonary arrest occurs, it is difficult to characterize it as an unforeseeable medical crisis. The illnesses that trigger the most in-hospital deaths in Canada today are heart and

cardiovascular disease, chronic lower respiratory diseases, cerebrovascular disease (e.g. stroke), and other degenerative organ failures (Statistics Canada, 2020). Deterioration from any of these illnesses typically leads to cardiopulmonary arrest, which is often the final outcome in disease progression. In other words, a patient may be dy*ing* of heart or chronic respiratory disease, but will most likely die from cardiopulmonary arrest in the literal sense when the weakened heart stops beating, perfusion and circulation are disrupted, and breathing ceases. In the hospital setting, cardiopulmonary arrest is known as an 'emergency' in the sense that CPR intervention must be immediate to sustain life, but it is importantly different from other medical crises for which immediate intervention is also medically necessary. For patients hospitalized with any of the aforementioned illnesses, cardiopulmonary arrest is reasonably expected and intervention is associated with significant variations in efficacy, benefit, and outcome that are dependent on patient status and prognosis leading up to and at the time of arrest (Bjorklund & Lund, 2019). In other words, the distal causes of in-hospital cardiopulmonary arrest (the distal causes being the underlying illness or conditions for which the individual is hospitalized) are significant determinants of the arrest itself, the need for CPR intervention, and the probability of successful intervention.

I argue that it is because of the foreseeability of cardiopulmonary arrest in patients hospitalized with serious and long-term illness that the 'emergency' designation does not exhaustively or accurately characterize the nature of the medical crisis. Consequently, the emergency medical protocol structure (which justifies the use of presumed consent) cannot apply. The distal causes of in-hospital cardiopulmonary arrest are typically known (depending on the patient's condition and the nature of their hospitalization) and provide

context for anticipating the crisis and initiating the consent process ahead of the event, such that presumed consent need not be the only available option for consent to intervention. Practically-speaking, the default use of presumed consent to CPR ignores the distal causes of arrest while focusing on rectifying the proximal causes (e.g. restoring heartbeat and breathing), and relevant factors such as diagnosis, prognosis, and patient condition immediately before and after arrest are lost in the rush to initiate emergency intervention. While there will always be limited ability to predict the onset or outcomes of medical crises regardless of how much medical evidence is available, many cases of in-hospital cardiopulmonary arrest could be foreseen as "the final common pathway in the process of death from all distal causes", in order to inform consent processes for resuscitation (Bishop et al., 2010, p. 64).

In this subsection I have explained how, in the hospital setting, the current default use of presumed consent for CPR intervention is predicated on the 'emergency' characterization of the medical crisis, and is supported by the notion of overarching general consent to routine medical interventions given the fact that the individual is hospitalized. I have challenged the assumption of emergency by arguing that, when we properly recognize in-hospital cardiopulmonary arrest as a health event that is on the horizon of foreseeability for certain groups of hospitalized patients, we can no longer accurately designate it as an unpredictable medical crisis which is exempt from ordinary consent processes. In sum, the foreseeability of in-hospital cardiopulmonary arrest (as the final outcome of certain common illnesses and conditions) contradicts the assumption of emergency on which default use of presumed consent is meant to be justified. Instead, the

foreseeability of the crisis should allow for informed consent processes to be initiated early and in anticipation of the event.

ii. Default Presumed Consent on the Basis of Benefit to the Patient

The model for default use of presumed consent to CPR intervention also relies on the assumption that CPR provides a benefit to the patient which is sufficient to justify foregoing the usual requirements of informed consent. This is a significant assumption that presumes a degree of medical consensus about the possibility of benefit to the patient, but that is not supported empirically. The assumption of benefit can be distinguished into two interdependent premises; first, that CPR is sufficiently beneficial that it outweighs any potential harms, and second, that the probability of receiving a benefit from CPR—survival—is itself significant (i.e. likely). Both premises of this assumption are in tension with the empirical facts of many cases of in-hospital cardiopulmonary arrest. Bishop et al. highlight how this tension exists in current norms of clinical practice:

> In truth, [CPR] is a medical intervention with reasonable success in some kinds of patients with certain kinds of diseases. Furthermore, it must be remembered that [CPR] also has miserable success rates in certain kinds of patients with some other kinds of diseases. A ward culture insisting on presumed CPR acts as though there is one entity, cardiopulmonary arrest, for which [CPR] is the answer. (Bishop et al., 2010, p. 65)

First, for patients who are hospitalized with terminal illness or multiple comorbidities, the possibility of surviving CPR is minimal. In fact, the rate of survival to hospital discharge after CPR for in-hospital cardiopulmonary arrest is 15%-20%, and closer to 10% or lower

for patients with serious underlying illness or frailty associated with old age (van Gijn et al., 2014; You et al., 2019). Second, if patients do survive CPR, there are multiple adverse outcomes that can result from prolonged lack of oxygen and disrupted circulation, as well as further injury from chest compressions, intubation, or defibrillation. Some survivors of CPR experience significant brain injury from ischemia, often resulting in cognitive impairments or permanent unconsciousness, which is more likely the longer resuscitation measures last (Welbourn & Efstathiou, 2018). These complications occur more frequently in elderly and chronically ill patients given that spontaneous return of circulation takes longer and recovery from vascular injury is typically slower (Stapleton et al., 2014). Patients who experience these complications often require long-term survival support, such as Advanced Cardiac Life Support (ACLS) measures like artificial ventilation and intravenous feeding, if they do not recover consciousness or independent breathing after CPR. Such complications, as well as permanent hospitalization, can significantly impact subjective quality of life for patients in ways that may, for some, exceed any benefit gained from survival.

CPR can be a lifesaving treatment for cardiopulmonary arrest that occurs as a result of an acute, possibly reversible illness, but empirical data shows that it is unlikely to be effective and can be actively harmful if the cardiopulmonary arrest occurs as part of the dying process from chronic illness or irreversible injury (Ross, 1991; Bishop et al. 2010). Both premises of the assumption of benefit from CPR—that a beneficial outcome (i.e. survival) is likely and that it is sufficiently beneficial to outweigh any harms from CPR—are therefore inconsistent with CPR outcomes in certain groups of patients. If the objective of default CPR is to uphold healthcare goals of promoting health and well-being

and preventing harm, empirical evidence reveals that this objective can only be achieved for a limited number of patients, and rarely those patients who are receiving end-of-life care. In sum, default use of presumed consent to CPR rests on faulty assumptions as CPR is typically not beneficial, and in many cases is actively harmful, so it cannot be assumed to provide a benefit in all cases.

iii. Presumed Consent to CPR in the Public Setting

Both assumptions of presumed consent to CPR—of emergency and of benefit to the patient—are at work in the out-of-hospital setting when an intervening bystander provides CPR to an individual in cardiopulmonary arrest without their explicit and informed consent. However, the radically different clinical circumstances between the in-hospital and public settings determine whether these assumptions can reasonably apply to justify initiating invasive intervention without informed consent. First, in the public setting, intervening bystanders do not have access to the ill individual's medical information and therefore cannot foresee the medical crisis nor recognize it as a potential symptom of their underlying condition. As I have explained previously, the context of a hospitalized patient's diagnosis and prognosis often provides sufficient information for attending clinicians to anticipate a cardiopulmonary arrest and understand its occurrence as part of the patient's health trajectory, thereby contradicting the assumption of emergency (in terms of unpredictability in addition to temporal urgency). By contrast, an intervening bystander is *epistemically limited* in their position as a non-professional bystander compared to a clinician who is familiar with a patient's condition. In the public setting, a bystander does not have sufficient knowledge to consider the distal causes of the ill individual's arrest, but can only act under whatever knowledge they may have of

the proximal causes of the arrest (e.g. blocked airway, weak or absent pulse, etc.) (Bishop et al., 2010). This problem is further complicated by the fact that, outside of a hospital, an individual in cardiopulmonary arrest is less likely to have a chronic or serious condition (diagnosed or not) of which the arrest itself is a symptom, as is the case for hospitalized patients. If an intervening bystander did somehow have access to the arresting individual's medical information (e.g. if a friend or family member were present and could relay what they know of the arresting individual's health status to the intervening bystander), this still may not provide any indication as to the distal causes of arrest which could help guide decision-making for intervention.

Because an individual's cardiopulmonary arrest in a public setting is both unforeseeable (to bystanders present at the time of crisis) and temporally urgent, it can qualify as a true emergency in that setting. The assumption of emergency is therefore a reasonable basis for justifying the use of presumed consent to CPR outside of a hospital, meaning that intervening bystanders are not acting on the basis of faulty assumptions by presuming consent to CPR due to temporal and situational constraints preventing an informed consent process.

The assumption of benefit from CPR is somewhat more complicated in the out-of-hospital setting. Again, because intervening bystanders are epistemically limited with respect to the ill individual's health status, diagnosis, or prognosis, they are not in a position to make any estimates about the efficacy or potential risks of CPR for that particular individual. Additionally, bystanders (who are not medical professionals) may not have the same degree of understanding about the risks and outcomes of CPR as clinicians to begin with, and therefore may not have empirical knowledge which would

contradict a widely-accepted assumption of benefit from CPR. These epistemic limitations are compounded by the situational constraints of a public medical crisis; a bystander does not have access to medical tools or support which could increase the possibility of survival or minimize harmful outcomes (such as those available in a hospital), but can only provide basic CPR (e.g. chest compressions or defibrillation with an AED if one is available) if they are to intervene at all. So, even if the bystander can secure a benefit to the arresting individual by preventing their death (if survival is indeed beneficial to them), they do not have the resources with which to also minimize any harms from CPR that may outweigh the benefit of survival.

Recalling the two premises of the assumption of benefit outlined in *(ii)*, a bystander's use of presumed consent to CPR is shaped by uncertainty about the *possibility* of benefit itself and about the possibility that the benefit is *sufficient* to outweigh any harms. As a result of the clinical circumstances in which they are acting and the epistemic limitations of their role, an intervening bystander's actions are forced towards that which is *most likely* to produce a benefit *of any kind*. One such benefit can be the possibility of later choice. The intervening bystander cannot know whether death provides a benefit or a harm to the individual, so intervening to prevent their death may secure the option for the individual to choose survival or death at a later time, whereas failing to intervene removes that option entirely (since the individual dies from cardiopulmonary arrest at that time)[4]. Though an assumption of universal benefit from CPR is still inconsistent with empirical evidence, the possibility of later choice is a plausible benefit of CPR which could be secured through the use of presumed consent in

[4] I thank Dr. Letitia Meynell for highlighting this interesting point.

the emergency public setting. This kind of benefit does not provide parallel justification for default presumed consent in the hospital setting because the patient's hospitalization and the resulting context of their cardiopulmonary arrest nearly eliminate the epistemic and situational constraints which produce the particular forced choice of action an intervening bystander faces.

Though current applications of the presumed consent model in public emergency scenarios do not present the same tension between fundamental principles of healthcare ethics as they do in the hospital setting, there is still a risk that intervening bystanders may compromise these healthcare principles through their actions. For example, since non-professional bystanders do not act under any code of professional ethics, the bystander could take advantage of the arresting individual's incapacity combined with the presumption of their consent to act in ways that violate the individual's bodily autonomy and non-medical well-being. There may be some cause for concern that presumed consent to CPR in a non-clinical setting can be loosely interpreted as presumed consent to any actions committed in the process of attempting resuscitation, and these interpretations may only be reinforced if the resuscitation is successful. I raise this as a potential issue for further analysis but it is not central to my position on the use of presumed consent in public settings.

Thus far in this subsection I have explained how the assumptions of emergency and of benefit to the patient may reasonably hold to justify the default use of presumed consent to CPR in public settings, when an intervening bystander is acting under distinct epistemic and situational constraints. I have also drawn out how these epistemic and situational constraints are importantly absent in the hospital setting, where clinicians have

greater context for anticipating a hospitalized patient's cardiopulmonary arrest and greater empirical data available on which to assess the possibility of benefit from CPR. Though bystanders' use of presumed consent to CPR presents different risks to prevalent principles of healthcare ethics (i.e. bodily autonomy, justice), the factors that ground presumed consent are more clearly in force in the public setting than they are in the hospital setting. I leave this issue open to further debate, however, since the ethical and epistemic nuances of the public emergency setting likely merit a closer analysis than what I have provided here.

II. MEDICAL FUTILITY

In this section I shift to exploring the second key bioethical concept, medical futility. In the simplest terms, medical futility applies when there is a medical goal, there is an action or intervention aimed at achieving the medical goal, and there is reasonable certainty that the action or intervention will fail in achieving the particular goal (Slosar, 2007). Medical futility is roughly defined in either quantitative or qualitative terms related to the nature of the goal being pursued (Slosar, 2007). Quantitative (also known as physiological or technical) definitions of medical futility relate to the physiological goals of a particular intervention (e.g. restored pulse or spontaneous respiration), while qualitative definitions relate to goals that are representative of some distinct value (e.g. preserved or improved quality of life). Early definitions of futility in resuscitation practice focused on the more easily-measured physiological parameters of a treatment's effectiveness; a treatment was futile if it could not restore a heartbeat, for example (Vivas & Carpenter, 2021). However, both quantitative and qualitative definitions of medical

futility demonstrate conceptual, empirical, and practical limitations when applied in the modern end-of-life care context.

In current practice, medical futility is commonly used as justification either for unilateral clinician decision-making in the absence of patient or SDM input, or as grounds for resisting patient or SDM requests for potentially non-beneficial or harmful life-prolonging treatment (Bagheri, 2008). Though patients and families can also appeal to the medical futility concept to inform and support their own decisions for end-of-life care (e.g. to request a DNAR orders), I am primarily concerned in this chapter with instances in which the concept is used to support unilateral clinician decision-making. These instances often produce 'futility conflicts' between clinicians and patients' families, thereby prompting ethical review or regulatory responses. For example, a recent futility conflict in Ontario motivated new policies and renewed discussion in the literature surrounding clinicians' appeals to medical futility to inform resuscitation decisions. In the 2008 incident that led to the *Wawrzyniak v. Livingstone* judicial case, the acting physician refused to provide CPR for the patient, an 88 year-old with multiple comorbidities and suffering from multisystem organ failure after a bilateral above-the-knee amputation for gangrene, on the basis that resuscitative attempts would "almost certainly not benefit" the patient (Wawrzyniak v. Livingstone. 2019, ONSC 4900). The physician determined that CPR was medically futile for the patient and assigned them a DNAR without input and despite objections from the patient's SDM. In 2019, it was ruled by Justice Cavanagh of the Supreme Court of Ontario that "refusing to offer a medical treatment for reasons of 'futility' does not constitute negligence or malpractice", despite new policies by the College of Physicians and Surgeons of Ontario (CPSO) which classify the unilateral

assignment of DNAR orders as professional misconduct (Vivas & Carpenter, 2021, p. 1; Wawrzyniak v. Livingstone, 2019).

This recent case, combined with issues of medical futility introduced by the COVID-19 pandemic, point to the important implications of the medical futility concept in current resuscitation practices and policies. In this section I first provide an overview of different versions of the medical futility concept and their limitations, and I draw out how inconsistent applications of the vague and ill-defined concept make it epistemically inaccessible and unable to be questioned by those patients subject to them. Finally, I describe and assess the ways in which the concept is applied in current in-hospital resuscitation practices and provide of an overview of some arguments in support of the concept's use in the end-of-life care context.

i. Technical (Quantitative) Definitions of Medical Futility

In end-of-life care practice, judgments of medical futility are often indexed to a physiological parameter of intervention success; for example, CPR can be considered futile for a patient who is unlikely to regain independent breathing due to weakened lung capacity below a certain threshold. Conceptually, technical definitions of futility are often considered more objective and less value-laden than qualitative definitions of futility, since they are indexed to "factual judgments" of intervention success rather than "value judgments" of intervention worth (Tomlinson & Brody, 1990, p. 1277). Clinicians can make technical judgments about the futility of CPR for certain patients according to their professional assessment of the patient's health status, which can be determined through certain medical measurements (e.g. blood pressure, renal function, heartrate, lung capacity, oxygen levels, etc.). It is thought that medical decisions made according to these

technical parameters of futility are less likely to incorporate clinician bias or individual values into practice and are therefore more reliable in high-pressure clinical settings, such as an in-hospital patient code (Vivas & Carpenter, 2021). This thinking has recently been incorporated into policy; in response to a 2019 judicial decision (*Wawrzyniak v. Livingston*), the College of Physicians and Surgeons of Ontario (CPSO) decided that physicians in Ontario "are to restrict themselves to the strict [physiological] definition of futility if they decide to unilaterally withhold CPR" (Vivas & Carpenter, 2021, p. 2; Hawryluck et al., 2016). In practice, physiological parameters are often seen as sufficiently objective and value-neutral to be reliable parameters for determining the appropriateness of CPR and supporting these decisions in professional or legal disputes.

However, the supposed value-neutrality of technical definitions of futility has been challenged in recent literature, including interesting discussions by Slosar (2007) and Bishop et al. (2010). First, Slosar argues that technical definitions of futility do have explicitly value-laden dimensions and are far from achieving the type of value-free, objective reasoning which is so prized by the positivist scientific method that guides modern medical research and practice (Slosar, 2007; Callahan, 2005). Clinical judgments about effectiveness and probability of success, and decisions made about which of these are worth or not worth pursuing, all contain non-scientific components that are inherent to the social institutions of science and healthcare (e.g. the language and communicative methods used, the ways medical questions are formulated and answered, the sources of knowledge and expertise referenced, and the availability of resources and tools from which to select) (Slosar, 2007). In other words, though certain medical parameters can be observed empirically and objectively measured, the clinical judgments designating any

given parameter as the minimum threshold for intervention efforts (e.g. lung capacity at or above 50%) incorporate values of some kind into the technical futility concept. Thus, it is not evident that technical versions of medical futility are entirely value-neutral. Similarly, Bishop et al. (2010) highlight that, even once a medical decision has been made (e.g. once a clinician determines that CPR would be futile for a particular patient), further decisions require clinicians' individual competence, expertise, and clinical experience to interpret changes in patient status and carry out any treatment plans. All of these "are value laden and any claim to the contrary is uninformed at best, and facetious at worst" (Bishop et al., 2010, p. 65). Thus, parameters for and judgments of technical medical futility are not value-neutral nor entirely objective, and it is not clear how they could be otherwise given the ways in which medical decisions are reached and carried out.

To clarify, I do not take Slosar's and Bishop et al.'s points about the limited objectivity of technical definitions of medical futility to indicate an inherent weakness in these versions of the concept. Medicine in general is a highly value-laden institution, and indeed one in which values (individual and collective) must play a pivotal role. Rather, the problem is that it is inconsistent for medical practice and current policies (like the one set by the CPSO) to rely on technical parameters of medical futility precisely for their objectivity and value-neutrality when it is not clear that they are or can be objective and value-neutral at all.

Technical definitions and parameters of medical futility also show empirical and practical limitations due to the immense variability in CPR outcomes and the lack of consensus about which outcome probabilities are tolerable. For example, some

researchers have compiled data on CPR outcomes to develop models for estimating when patients are unlikely to benefit from resuscitation attempts, but these provide only a rough guide for predicting patient outcomes and are based on specific definitions of survival 'with good outcomes' (e.g. neurologically intact, preserved mobility, etc.) that others may not adopt (Ebell et al., 2013; Ebell et al., 2011). If survival after CPR is a parameter for intervention success, it is dishonest to ever designate CPR as 100% physiologically futile for any particular patient since successful resuscitation "relies on a balance of probabilities rather than objective certainty" (Vivas & Carpenter, 2021, p.1). Two patients in the same state of ill health may respond in radically different ways to the same intervention—CPR may restore heartbeat in one patient but not the other, or may result in permanent unconsciousness for one patient while producing no long-term complications for the other.

Besides the inherent uncertainty in relying on such probabilities, it is difficult to set a universal threshold of technical futility without assuming universal levels of risk tolerance. While it is rarely feasible to ascribe a zero percent chance of survival, something as low as a 1% chance of survival may be sufficient for patients or clinicians to deem resuscitation measures worthwhile when facing a 100% chance of death without CPR, while others may consider a 1% chance of survival far too minimal to warrant invasive intervention (Kidd et al., 2014). Despite the amount of available empirical data on CPR outcomes, it is not clear how to set reasonable parameters for designating CPR as technically futile without simply hedging bets about particular patients, or assuming an erroneous consensus about which outcomes would indicate success.

ii. Qualitative Definitions of Medical Futility

Given the limitations of depending merely on physiological parameters and their probabilities for determining futility, some defend more holistic conceptions of futility that take into account how certain physiological outcomes would affect functional capacities, levels of pain and discomfort, and quality of life. Qualitative conceptions of medical futility became predominant in the literature due to recent emphasis on patient perceptions of and goals for quality of life, particularly in the end-of-life care context (Rodriguez & Young, 2006; Slosar, 2007; Vivas & Carpenter, 2021). Qualitative judgments of medical futility concern "the value of a given effect that in all probability will occur"; the probability of survival is not the only relevant factor (Slosar, 2007, p. 69). Rather, the 'cost' of survival is an important consideration in determining futility since the range of harmful outcomes associated with technically successful CPR—including anything from fractured ribs to liver lacerations to significant brain injury—directly impact the quality (and likelihood) of long-term survival after resuscitation (Kidd et al., 2014). Qualitative parameters for medical futility better capture these realities and indicate that CPR is futile when, in general terms, it is likely to produce harms that will worsen a patient's quality of life.

However, qualitative versions of the medical futility concept have also been criticized. The standard argument against qualitative futility goes: any judgment that CPR is "futile" and should be withheld on the basis that low quality of life after CPR is "not worth" pursuing, is a value-judgment which rightfully belongs to the patient, not the clinician. Some argue that allowing clinicians to base decisions about withholding CPR on their own values, beliefs, and assumptions about patient quality of life invokes an

unrestrained paternalism in patient-physician relationships which limits patients' autonomous choices of care (Tomlinson & Brody, 1990; Vivas & Carpenter, 2021). Qualitative conceptions of futility are thus opposed on the basis that clinicians' value-judgments may override the patient's and threaten patient autonomy.

Additionally, and similar to criticisms about technical definitions of futility, there is no consensus about what constitutes an 'acceptable' quality of life following CPR, with which to set widely applicable policies for resuscitation. This problem is complex. First, the notion of 'quality of life' is highly laden with social and personal (mis)perceptions of disability and values informed by these, such that individuals may all have different (and, to varying degrees, inaccurate) ideas about which type of quality of life is worth preserving, pursuing, or avoiding. While some may have perhaps a better sense of how particular medical outcomes or conditions affect quality of life (i.e. through their lived experiences), it can be difficult for patients and clinicians alike to estimate quality of life after medical intervention in a way that does not collapse into ableist assumptions. For example, several studies have identified that, despite their clinical experience, clinicians often significantly underestimate the quality of life of disabled patients and frequently make inaccurate predictions about quality of life following particular medical outcomes (Kothari & Kirschner, 2006; Janz, 2019). Ideally, estimations of quality of life and judgments about whether a particular quality of life is desirable are the patient's to make as part of the consent process. However, there remains the risk that patients' own notions of quality of life are not free of ableist bias, either. I return to this issue in Chapter 3.

Second, as Slosar (2007) points out, attempts to designate an 'objective', standardized threshold of qualitative futility are conceptually misguided because such

standards could not be sensitive to the plurality of moral sensibilities, rationalities, and hierarchies of value by insisting on a singular, homogenous system of moral value and reasoning about quality of life. In other words, the notion of quality of life cannot be standardized in a way that would capture all or even most of the different conceptions of what is required for good quality of life. Rather, any standardized notion of qualitative medical futility on which there is general consensus is likely to merely reflect widespread ableist bias. To sum up the problem of quality of life as it pertains to qualitative medical futility, it seems problematic and risky to use the highly subjective notion of quality of life as a reliable or standardized indicator of intervention appropriateness, particularly when patients cannot provide their own perspectives on quality of life (e.g. during an in-hospital code).

Qualitative definitions of medical futility are thus challenged on political grounds (in terms of patient autonomy versus clinician authority) as well as being conceptually limited in scope. Practically-speaking, qualitative judgments of futility are also dependent on probability estimates of highly variable CPR outcomes and individual patient responses to intervention, and are consequently limited in their applicability as reliable guidelines for medical action (in the same way that technical thresholds for medical futility are limited by "the uncertainty inherent in the use of group-based statistics to predict outcomes in particular patients" (Bishop et al., 2010, p. 63). In short, not only is it exceedingly difficult to set a standardized threshold of acceptable quality of life that does not engender unchecked ableism in resuscitation practices, any predictions about patient quality of life following CPR are, at best, probability estimates about highly variable medical outcomes and their possible impacts on daily life.

iii. Medical Futility in Practice

At its core, a clinician's judgment that resuscitation is medically futile is a judgment that CPR is not worth attempting on a particular patient for *x* reason and based on probability estimates about *y* outcome. I argue that because there is no clear and definitive notion of medical futility by which to consistently and reasonably determine when withholding CPR and invoking DNAR is appropriate, protocols and decisions based on appeals to medical futility are inconsistent and contingent on individual clinicians' assessments of *x* reasons and *y* outcomes. This conceptual inconsistency is problematic in this context[5] because it may inhibit shared understanding between patients and clinicians about the reasons for foregoing potentially life-saving intervention, thereby limiting the patient's role as an informed decision-maker in their own care.

Furthermore, it is not clear that there *could* be a clear and definitive notion of medical futility which is not inconsistently exclusionary or inherently ableist, given that medical futility is typically indexed to measures which are contingent on group-based statistics or general consensus about quality of life. These problems of definition render the medical futility concept epistemically inaccessible and unable to be questioned by those subject to them (i.e. patients), while equipping clinicians and healthcare authorities with abundant decision-making power over patient life and death. This is of particular concern considering that certain groups of patients are already made vulnerable by ableist, racist, misogynist, classist, and otherwise contingent mechanisms in healthcare and adjacent social systems, or that usual protocols can be drastically adjusted to

[5] I thank Dr. Kirstin Borgerson for pointing out that conceptual inconsistency is a problem for many other concepts in the medical domain (e.g. disease and disorder concepts) and is therefore not unique to the context I am discussing.

accommodate situational constraints (e.g. changes to DNAR protocols in light of medical resource shortages related to the COVID-19 pandemic[6]).

Having explained the inconsistent theoretical understanding of the concept that I see as problematic, here I provide an overview of arguments by Bishop et al. (2010), Tomlinson and Brody (1990), and Vivas and Carpetner (2021) in support of applying medical futility in practice despite its vague and ill-defined theoretical basis. When a patient experiences cardiopulmonary arrest in the hospital setting, CPR may be withheld as inappropriate, unnecessary, or unreasonably harmful—in other words, futile—particularly if the patient is receiving end-of-life care. Futility judgments of this kind are indexed roughly to a goal of harm reduction or harm prevention (or non-maleficence, using language from Beauchamp and Childress (2001)). The medical futility concept is thus important in some sense for pursuing fundamental healthcare objectives of preventing harm and promoting well-being (if the latter can be understood as an outcome of preventing harm). DNAR orders therefore function as practical applications of the medical futility concept with which patients, SDMs, and clinicians can direct that CPR be withheld on the basis that it will produce harm.

To this point, Bishop et al. (2010) argue that applications of medical futility (e.g. orders or requests for DNAR status) give practical validity to clinicians' and patients'

[6] During particularly intense waves of the COVID-19 pandemic, some clinicians in the UK and in the US assigned DNAR status to COVID-19 patients based on atypically low standards for technical medical futility. These instances revealed that, under situational or resource constraints, thresholds of medical futility can be adjusted on a sliding scale to include fewer individuals as appropriate recipients of CPR. The COVID-19 pandemic presented a particularly interesting case study given that legitimate resource constraints under states of emergency motivated many of these policy changes but, at the same time, patients with severe COVID-19 symptoms and especially those with underlying health conditions showed a CPR survival rate of less than 3%. Some COVID-19 patients were therefore reasonably considered inappropriate recipients of CPR per some technical parameters of medical futility (Hayek et al., 2020). Joseph Fins provides interesting discussion on this topic in "Resuscitating Patient Rights during the Pandemic: COVID-19 and the Risk of Resurgent Paternalism" (2020).

"intuitive sense that not all interventions work, and accordingly not all interventions should be triggered at the *patient*'s discretion" (p. 64, emphasis added). I add to Bishop et al.'s point here that these applications help to indicate that not all interventions should be triggered at the *system*'s "discretion", either. It is already understood that not all interventions should be triggered merely at the clinician's discretion—hence the regular requirements of an informed consent process for initiating intervention. Yet a default medical action system (e.g. default full code system that mandates CPR) means that intervention is triggered by the system itself rather than by any decision-maker's discretion, thereby negating the selectivity of patient-centred care and contradicting any 'intuitive sense' that not all interventions work. In response, DNAR orders and other medical futility judgments "were designed to address the excesses that presumed consent to CPR engender", in order to reaffirm the intuitive sense that not all interventions work or should be triggered at the system's "discretion" (Bishop et al., 2010, p. 65). DNAR orders therefore allow patients or SDMs to have a role in the decision-making process for resuscitation, that is denied them by default full code systems. In the end-of-life care context in particular, appeals to medical futility can help to make it clear that CPR is a medical option which can be refused but on which patients, clinicians, or medical action systems cannot insist.

Bishop et al. concede that there is indeed minimal consensus about how best to define medical futility and attempts to find foolproof formulations of futility will fail given the inherent variability in CPR outcomes, perspectives on quality of life, and subjective goals for end-of-life care. However, they conclude that we should not concede

that the uncertainty around medical futility means that the concept has no place in modern practice:

> Rather than saying we live in a post-modern world and certainty is not possible and, therefore, that the concept of futility should be abandoned, we instead propose that medicine must acknowledge and own its inherent uncertainties. Such candor on the part of the medical community could begin with our admission that not all interventions are medically feasible. We are victims of medicine's successes, and the unintended consequences for these successes are practices like in-hospital universal, presumed consent to CPR that result in patient expectations on which medicine cannot deliver. (Bishop et al., 2010, p. 65).

From Bishop et al.'s perspective, medical futility has practical value in motivating an acceptance and a recognition of the fallibility and limitations of medicine, and thereby curtailing the false medical optimism that both motivates and is reaffirmed by default resuscitation practices.

Alternatively, Tomlinson and Brody (1990) argue primarily from the clinician's perspective and emphasize that clinicians are and ought to be justified in applying medical futility per their discretion, and that this is important for maintaining the integrity of the medical profession. They point out that clinicians' authority to place at least some limitations on the types of treatments provided to patients is generally recognized, and that any such limitations require an appeal to value judgments of some kind. In fact, "if [clinicians] have any rightful control over the interventions they provide, it is *only* because they have the authority to act on judgments of value" (Tomlinson & Brody, 1990, p. 1277, emphasis added). Clinicians can thus rightfully withhold CPR according to

their value-judgments that CPR would be medically futile (in either a technical or qualitative sense) for a particular patient, according to Tomlinson and Brady. Justifying particular appeals to medical futility then becomes a matter of identifying *which* value-judgments clinicians may use in deciding when to withhold CPR.

Tomlinson and Brody explain that clinicians are justified in withholding a particular treatment according to judgments that the end the treatment will achieve is not one that the clinician is obligated to pursue (Tomlinson & Brody, 1990). For example, a clinician is justified in refusing to provide an arm cast that a patient requests as treatment for a skin rash because the end this will achieve—the patient's sheer and uninformed satisfaction—is not one the clinician is obligated to pursue. This distinction about which ends clinicians are obligated to pursue, given their role as medical professionals, entails that "social conceptions of reasonableness and of the worthy ends of medicine" play a significant role in medical futility judgments and DNAR decisions (Tomlinson & Brody, 1990, p. 1278). In other words, the responsibilities and obligations of medical professionals extend only so far as the collective understanding of what medicine (specifically, end-of-life care) can and should achieve. According to Tomlinson and Brody's analysis, medical futility judgments and resulting DNAR decisions are statements that CPR will not achieve an end which medical professionals ought to pursue, corresponding to social conceptions of what should be achieved by intervention (e.g. promotion of well-being). In turn, these statements affirm and uphold the integrity of the medical profession by delineating its worthy ends.

Considering the patient's perspective, Tomlinson and Brody provide additional support for medical futility applications in arguing that "the power to limit the range of

reasonable patient options [is] a tool that physicians need to serve effectively as advocates for the patient's autonomy" (Tomlinson & Brody, 1990, p. 1280). Addressing specifically the concerns that clinicians' value-judgments of medical futility may override the patient's values and thereby restrict their autonomy, Tomlinson and Brody highlight that power, understood here as decision-making authority in the physician-patient relationship, is often misperceived as a "zero-sum game" (Tomlinson & Brody, 1990, p. 1279). Power is incorrectly thought to be exchanged between patients and clinicians as one gains it and the other loses it. By this model, clinician abuses of power occur when patient autonomy is wholly compromised, and patient autonomy is enhanced only when clinician authority is restrained or diminished (Tomlinson & Brody, 1990). Instead, Tomlinson and Brody articulate a model of shared power whereby the clinician provides a range of care options that is reasonably restricted to those which can actually (to the clinician's best knowledge) serve the patient's best interests. Withholding CPR that is unlikely to serve the patient's best interests (e.g. if the patient is dying of severe or incurable illness) is not, therefore, an unreasonable restriction of care options. Rather than overriding the patient's autonomy, the restriction of care options on the basis of medical futility actually promotes it.

Finally, Vivas and Carpenter (2021) support the medical futility concept as an affirmation of the patient as priority. In one section of their discussion, they explore the possibility that resuscitation attempts may be beneficial regardless of their technical effectiveness, as part of personal or social understandings of the death process and of our obligations to the dying. For patients' families or healthcare teams, CPR attempts may help to maintain the sense that one has done everything possible to prevent or delay

death, thereby supporting dying patients to the greatest extent possible and fulfilling what may be seen as 'owed' to them. Technically unsuccessful CPR "might still act as a sort of contemporary 'death ritual' in the modern medical environment" (p. 2), according to Vivas and Carpenter (2021). However, they conclude that this practice is antithetical to fundamental medical goals of promoting health and preventing harm for the dying patient (in cases where CPR does not or cannot accomplish either). Providing futile intervention for the sake of personal or social relief to survivors but at the cost of the patient's best interests is an obvious "failure in patient-centredness" (p. 2). Clear and empathetic appeals to medical futility are thus important for supporting patients' families and healthcare teams in processing the patient's dying and death, including understanding why intervention would do more harm than good, while ensuring that the patient's best interests (e.g. harm prevention) remain the priority.

Though it remains to be clearly defined, the futility concept has long been present in the collective medical consciousness and seems important for designating when and which types of intervention are no longer serving the goals of medicine, be they technical or otherwise. Here I have discussed several arguments for applying the medical futility concept in practice despite its vague and ill-defined theoretical basis. In short, medical futility may be a valuable concept with meaningful use in medical decision-making, particularly in order to inform efforts to reduce harm and promote well-being in end-of-life care. The challenge remains of getting clear on what is and ought to be captured by the medical futility concept in order to promote shared understanding between clinicians and patients about the rationale behind DNAR orders, and better enable the patient's role as a decision-maker for resuscitative intervention.

In this chapter I have explored the key bioethical concepts framing the CPR/DNAR debate—presumed consent and medical futility—and have argued that the inconsistent theoretical understanding and practical application of these concepts promotes contradictory aims and in many cases compromises prevalent principles of healthcare ethics. The two concepts exist in tension in current practice because they motivate opposite approaches to resuscitation—a non-selective, default approach to providing CPR exists in tension with a selective, highly contingent approach to withholding CPR. In evaluating these concepts, I have drawn out that the concerns motivating debate about the appropriateness of CPR and the ethical risks of presuming universal consent to CPR—concerns about beneficence, non-maleficence, and respect for patient autonomy, in particular—are what prompt the need for DNAR orders. At the same time, justifying clinicians' DNAR decision-making (in practice and in subsequent judicial or regulatory responses) according to vague and ill-defined notions of medical futility limits the potential for patient understanding and informed, autonomous choice. In Chapter 3, I will discuss clinical and social norms which both inform and emerge from these contradictory concepts in end-of-life care, and I will explore how these result in accessibility barriers that limit the extent to which DNAR orders can address the "excesses" produced by current resuscitation practices (Bishop et al., 2010, p. 65).

CHAPTER 3: EPISTEMIC AND STRUCTURAL BARRIERS TO DNAR ACCESS

The previous chapter, devoted to exploring the central bioethical issues framing the CPR/DNAR debate, focused primarily on resuscitation practices from the clinician's perspective. Addressing the concepts of presumed consent and medical futility from a clinical perspective is helpful for elucidating the roles of clinicians and healthcare authorities in resuscitation practices, but it does not capture the challenges that patients and families may face in making their own decisions about end-of-life intervention. In this chapter, I change perspectives and discuss the potential barriers to equitable and meaningful access to DNAR orders for Canadian patients. I argue that, despite being formally available (i.e. legal) as a healthcare option in Canada, DNAR is not a live and meaningful option when there are barriers to understanding, justifying, and applying these orders. When DNAR is not a live and meaningful care option, there is greater risk of *overintervention* for dying patients which, as I argue, compromises prevalent healthcare principles of beneficence, non-maleficence, justice, and respect for patient autonomy.

I begin in the first section by outlining the problem of overintervention in end-of-life care. Drawing from insights in Atul Gawande's *Being Mortal* (2014) and Daniel Callahan's "Death: 'The Distinguished Thing'" (2005), I first define medical overintervention and then provide examples of how it persists in end-of-life care in Canadian hospitals. Next, I draw out how in-hospital resuscitation practices facilitate overintervention while epistemic and structural barriers to DNAR access leave patients and laypeople poorly situated, epistemically- and practically-speaking, to refuse it. Finally, I conclude the chapter with an overview of some potential solutions to

minimizing these barriers in order to prevent overintervention and better uphold the principles of beneficence, non-maleficence, justice, and respect for patient autonomy in the end-of-life care context.

i. Outlining the Problem: Overintervention in End-of-life Care

Based in the US, Dr. Atul Gawande writes extensively about the issue of overintervention and the 'medicalization of dying' in *Being Mortal* (2014). Gawande provides American national healthcare data and his own experiences as a practicing oncologist to show that hospitalized, terminally ill Americans are subjected to ineffective high-intensity care in the last months of life, only to die expected deaths from their known illnesses or complications. Gawande highlights how current medical practices and ward culture often encourage an active and ongoing battle against death but provide patients and families with little opportunity to revaluate goals of care, seek alternative care options, or opt out of treatment altogether. The result is what Gawande calls a "warehoused oblivion" in which many terminal[7] patients spend their final days or weeks, being kept alive by a litany of medical tools (e.g. advanced cardiac life support, artificial feeding and ventilation, etc.) but rarely conscious or comfortable (2014; p. 188). Gawande sees overintervention in end-of-life care (specifically in oncology, Gawande's specialization) as unrelenting medical efforts to delay or prevent a patient's death which has become imminent and inevitable. Current trends of overintervention contribute to what Gawande describes as the "medicalization of dying"—the infiltration of medicine

[7] By 'terminal', 'terminally ill', or 'terminal illness' I am referring to patients with a "grievous and irremediable medical condition", which is defined in Bill C-14 (the Canadian legislation on medical assistance in dying) as including: a serious and incurable disease, illness, or disability; an advanced state of irreversible decline in capability; and the person's natural death has become reasonably foreseeable due to all of their medical circumstances, without requiring that a prognosis has been made as to the length of time that they have remaining (Government of Canada, 2021).

and medical technology into what were previously shared, familial or community-based practices of caring for the dying until their natural death (2014).

The overintervention in end-of-life care Gawande discusses is a product of the recent shift in medical culture which Daniel Callahan describes in "Death: 'The Distinguished Thing'" (2005). Callahan draws out a connection between the modern medical research drive and current medical practices aimed at defying death:

> The research push treats death as a contingent, accidental event that can be done away with, one disease at a time... That kind of zeal spills over into clinical practice. Force-fed by research turned into technology and undergirded by medical education and clinical acculturation, good medicine saves lives. It does not give up. It refuses to negotiate with death. (p. S6)

Callahan argues that modern research interests somewhat replaced a postwar "technological imperative to use every means possible to save life", that was motivated by rapid medical progress and collective moral concern for the sanctity of life principle (2005, p. S6). Today, aggressive, research-driven medicine conflicts with what Callahan identifies as the other side of clinical practice—palliative care—which prioritizes the relief of pain and suffering in a patient's final phase of life. This sort of practice requires that clinicians, patients, and families accept death as "an unavoidable part of life" (p. S6), but it is often overshadowed by the modern medical imperative to chip away at death's inevitability.

According to Callahan, there is a schism in current medical practice between ambitious curative medicine and minimalist end-of-life care, that produces competing medical goals in the care of dying patients:

> But is there an inconsistency in helping someone die well when death is on its way while simultaneously seeking a cure that will benefit future patients dying from the same disease? There is no logical inconsistency, narrowly understood, but there is a powerful psychological clash. It pits the value of accepting death when a particular death is unavoidable against rejecting death as a matter of principle for a research-ambitious medicine. (2005, p. S6)

Though significant progress has been made in improving palliative care since it began to formally develop in the late 1960s, medical research interests still divide medical efforts in end-of-life care while patients' experiences and welfare hang in the balance (Callahan, 2005). Overintervention is thus a product of the ambitious medical imperative to cure and resist death, that largely shapes current practice.

That said, overintervention in end-of-life care is driven by multiple variables, including (but not limited to) inflated or uninformed patient or family expectations for care, clinician concerns about liability for malpractice, research incentives, healthcare payment and cost systems which reward doing more, outdated practice habits or default action systems, and overarching hospital and medical cultures of unyielding optimism or resistance in the face of death. These various driving forces are, as Callahan argues, "more incremental than decisive in nature but, taken together, strong in their aggregate force" (2005, p. S6). Clearly, overintervention is not a simple problem. Nor is it unique to the end-of-life care context; the tendencies towards excessive testing and screening, overdiagnosis, and overtreatment in modern North American medicine are topics of growing clinical and ethical importance.[8] There are increasing international efforts to

[8] See Ebell and Herzstein's "Improving quality by doing less" series of editorials on overscreening, overdiagnosis, and overtreatment in American Family Physician (2015).

reduce practices that are likely to provide limited benefit and potential harm to patients, including the Choose Wisely public campaign which provides resources and recommendations for choosing appropriate, minimalist, and evidence-supported treatment plans (Siwek, 2015; Choose Wisely Canada).

In general, overintervention is recognized as a problem because it threatens medical principles of beneficence and non-maleficence, primarily, while compromising the principles of justice and respect for patient autonomy in important ways. There is, I think, a growing understanding that unreasonably or unjustly keeping patients alive can be as harmful as intentional negligence or malpractice, and is thus as worthy of ethical concern. By providing *too much* intervention for dying patients, medical practice quickly surpasses the point of providing benefit and preventing harm, and instead compromises these fundamental healthcare goals in a relentless effort to prevent death.

Though the increasing attention towards the issue of overintervention is promising, many of Gawande's and Callahan's insights about overintervention in end-of-life care hold true for current Canadian healthcare practices—in-hospital resuscitation practices, specifically. Canadian patients who are hospitalized with terminal illness often receive "advanced curative or life-prolonging treatments that are not consistent with the goals of care", including CPR when cardiopulmonary arrest occurs (Downar et al., 2015, p. 271). These life-prolonging treatments typically continue until the patient dies or is discharged from the hospital (Downar et al., 2015). These treatments are intensive and are unable to prevent death for terminal patients (though they may delay death by several days or weeks, often at great cost to quality of life) and thus constitute the sort of overintervention Gawande identifies (2014).

There is awareness of overintervention in Canadian end-of-life care for more than a decade now; in a 2005 study, Canadian intensive care practitioners candidly reported that 'futile care' was indeed provided in their wards despite practitioners' confidence that the patient would not benefit nor recover and would likely suffer harms from the aggressive treatments (Palda et al., 2005). Here I want to highlight the important connection between overintervention and medical futility; providing treatments or interventions that are deemed unlikely to be successful or beneficial—in other words, that are futile per a typical definition of medical futility—contributes to overintervention as a norm in medical practice. The provision of medically futile intervention *is* overintervention, given that it cannot or is unlikely to achieve a particular medical goal (i.e. per the simplest definition of medical futility I discussed in Chapter 2) and therefore surpasses what can be considered a reasonable degree of intervention. Determining what counts as overintervention thus requires applying some notion of medical futility.

Medical futility helps to elucidate what and when intervention qualifies as overintervention but it is presumed consent that plays a significant role in *facilitating* overintervention in end-of-life care specifically. As I discussed in Chapter 2, the default full code system in Canadian hospitals mandates that all patients in cardiopulmonary arrest receive the full extent of CPR measures (unless directed otherwise). The full code system relies importantly on default presumed consent to CPR. For many terminally-ill patients, CPR is considered medically futile because it will not cure the patient's condition or improve their quality of life, it provides only minimal chance of technical success, and it is likely to inflict harm. Providing CPR in these circumstances—when it is considered medically futile—constitutes overintervention. Therefore, the full code system

mandates overintervention for those patients for whom CPR is considered medically futile, and default presumed consent facilitates this overintervention. To be clear, default presumed consent is not the *cause* of overintervention when cardiopulmonary arrest occurs (again, there are multiple factors driving patterns of overintervention in medical practice in general) but it makes overintervention possible and legally justifiable when patient or SDM input are absent. At the system level, presumed consent to CPR is a 'decision' which can only be overridden by a DNAR order (a patient's or SDM's decision), which is prevented when there are barriers to patient/SDM decision-making.

To sum up, in-hospital resuscitation policies constitute one important norm of overintervention in end-of-life care because they mandate the provision of intensive, harmful, and nonbeneficial attempts to prevent death in some patients for whom death is imminent and inevitable. There are two important points to be drawn from what I have outlined thus far. First, some notion of medical futility is necessary for understanding and qualifying CPR as overintervention for hospitalized, terminal-ill patients. Second, since in-hospital resuscitation policies (e.g. full code systems) rely on default use of presumed consent to CPR, overintervention in end-of-life care is facilitated by presumed consent. In the next section, I argue that overintervention in end-of-life care persists in part because patients and the lay public are poorly-situated to refuse or resist it. Specifically, I identify potential epistemic and structural barriers to DNAR accessibility which may limit patients' ability to refuse CPR, thereby perpetuating overintervention in in-hospital resuscitation practices.

ii. Epistemic Barriers to DNAR Accessibility

First, I argue that the DNAR order is a significant tool for preventing overintervention in end-of-life care because it interrupts the medico-social imperative to 'save the life' at all costs and in all cases. I explained in Chapter 1 how DNAR orders can be assigned unilaterally by clinicians according to their judgments of medical futility, and that this raises significant ethical concerns given the ambiguous and inconsistent nature of the medical futility concept. The problems of definition surrounding the medical futility concept do not negate the important practical value of DNAR orders, however, as patients' means for preventing unnecessary or unwanted intervention when death is imminent. When patients and families are supported in choosing and implementing DNAR orders as part of their end-of-life or advance care planning, they are in a position to refuse or prevent overintervention according to their own notions of what and when intervention is medically futile.

As such, a patient's or SDM's ability to refuse CPR is limited when DNAR orders are inaccessible. DNAR accessibility determines the extent to which DNAR orders are a live and meaningful healthcare option. By 'live and meaningful' I mean that it is a healthcare option which can be actively selected, justified, and enacted, and which results in timely medical outcomes that are supported by legal and other social regulatory systems. A live and meaningful healthcare option must therefore be legal (i.e. according to Canadian healthcare laws), but its legal permissibility does not necessarily ensure that it is live and meaningful. Thus, although it is legal for patients and SDMs to request a DNAR order in Canada, DNAR is not a live and meaningful option if and where DNAR accessibility is limited.

DNAR accessibility can be quantified along two axes. First, patients and SDMs must have awareness and understanding of DNAR, its purpose, and the medical circumstances in which it is an appropriate healthcare option. This awareness and understanding constitute what I call the *epistemic* axis of DNAR accessibility. Second, patients and SDMs must be able to select DNAR from amongst a variety of end-of-life care options, have this decision documented in some way, and finally have it respected and enacted in the event that the patient experiences cardiopulmonary arrest. These elements make up the *structural* axis of DNAR accessibility. Both the epistemic and structural elements of DNAR accessibility may vary between provincial and territorial healthcare systems but, as I will discuss, the structural elements are more significantly dependent on province-, territory-, or institution-specific frameworks and initiatives for advance care planning. On the other hand, the epistemic elements of DNAR accessibility are largely shaped by broader social habits of communication and education about hospitalization, dying, and death.

I will begin by discussing what I identify as potential epistemic barriers to DNAR accessibility, drawing from empirical evidence where available as well as some anecdotal evidence (e.g. what I see and hear as an adult in the Canadian population). Awareness and understanding of DNAR, its purpose, and the medical circumstances in which it is an appropriate healthcare option require some minimal knowledge about the realities of hospitalization and death from terminal illness or injury. In other words, patients and laypeople must have some general idea of what dying in the hospital entails, in order to be prompted to think about DNAR as a care option that may be appropriate for them. It is not clear that this knowledge is common or readily available, for two main reasons.

First, death and dying are not as commonly witnessed as they once were. Both Gawande (2014) and Callahan (2005) point out that the 'medicalization of dying' has reduced how much laypeople are exposed to death and dying; what was once a regular fact of life has become increasingly sequestered to the clinical context (e.g. in hospitals or long-term care institutions) where few people witness it. Death and dying have become largely privatized whereas they used to be familial or communal events, and this is contributing to a collective loss of social or cultural understanding of these experiences, particularly since these experiences are increasingly medicalized in highly complicated ways (i.e. with artificial life support measures) (Gawande, 2014).

Second, social habits of avoiding the 'grim' or 'impolite' topics of dying and death may further reduce the extent to which laypeople are realistically informed about these inevitable experiences. These topics rarely come up in casual conversation and, though they can certainly be emotionally-laden and difficult to talk about it, common reluctance to honestly examine these experiences reinforces a collective lack of understanding about the dying process. Recent provincial initiatives to encourage advance care planning and general discussions about dying and end-of-life care (e.g. Alberta's policy to implement Goals of Care orders in 2014) have made some impact on the topic's prevalence amongst laypeople, but rates of advance care planning, where they are tracked, remain low and do not indicate that these discussions happen all that frequently (Digout et al., 2019; Wilson et al., 2013). Callahan summarizes these epistemic barriers as such:

> No doubt advance directives have never had the impact hoped for because most people resist facing up to their eventual death (even the preparation of ordinary

> wills is widely neglected). Education and publicity can make a dent in the otherwise poor figures... but the fact that most deaths are not seen up close and occur for the most part in old age does not push the reality of death in one's face the way it once did. If you don't want to think about it, there are lots of ways to look in other directions. (2005, p. S7)

Given current social (and to some extent, cultural) habits around death and dying, patients and laypeople generally are unlikely to know what hospitalized dying and death may entail until they themselves experience it (and then it can be experienced only once). Such knowledge is needed for understanding the circumstances in which DNAR would be appropriate—medical circumstances in which death has become imminent and inevitable—and for understanding how likely these circumstances become as certain fatal illnesses or conditions progress.

Additionally, patients and SDMs need some specific knowledge about in-hospital resuscitation measures in order to understand when and why DNAR would be practically valuable. If terminally ill patients or their SDMs do not know about the likelihood of in-hospital cardiopulmonary arrest, default resuscitation practices, and the risks and outcomes of these practices, they are not sufficiently informed to make their own value judgments based on probability estimates about intervention outcomes—their own judgments of medical futility, in other words. As I discussed in the last section of Chapter 2, DNAR orders function as a patient's or SDM's statement that CPR is medically futile per their notion of medical futility. Patients and SDMs do not have the requisite knowledge to make judgments that CPR would be harmful, minimally beneficial, or futile in any sense if they are uninformed about CPR and its causes and outcomes.

Even if patients and SDMs are generally aware that clinicians will automatically initiate CPR for in-hospital cardiopulmonary arrest, they may have misunderstandings about the limited effectiveness and potential consequences of CPR. Indeed, such misunderstandings are common amongst the lay public and result in part from exaggerated portrayals of resuscitation success in popular media (e.g. medical TV shows like Grey's Anatomy or Scrubs), and from the widespread public uptake of layperson CPR/First Aid training initiatives that do not often emphasize the significant risks of CPR (Rosoff & Schneiderman, 2017). The fact that CPR is the default intervention (if this is widely known) may even imply to patients and SDMs that it is likely to be successful. If patients or SDMs are unaware of the limited potential for success and significant risk of harms associated with CPR for in-hospital cardiopulmonary arrest, they have no reason to consider refusing the intervention on any basis of medical futility.

In sum, to be epistemically equipped to opt for a DNAR order, patients and SDMs need general knowledge about what death and dying may look like in the hospital, and more specific knowledge that i) CPR will be initiated by default for in-hospital cardiopulmonary arrest; ii) that this medical crisis is the most likely final outcome of distal and proximal causes in terminal illness; and iii) that CPR has limited success with significant risks for certain patients. Patients and SDMs must have the minimum knowledge with which to make their own judgments that CPR would be medically futile (per some notion of medical futility) in order to choose a DNAR order and refuse the intervention. When this knowledge is unavailable or inaccessible to patients and laypeople generally, DNAR is epistemically inaccessible.

By contrast, clinicians, particularly those who provide emergency or end-of-life care in a hospital setting, are more likely to possess realistic knowledge about in-hospital dying and death, given their proximity to dying patients. Clinicians who provide end-of-life care know what dying can look like, what it demands and takes from patients, and what functional or emotional consequences can come from efforts to delay it, given that they witness it regularly (or at least more regularly than most). Clinicians are required to initiate CPR for in-hospital cardiopulmonary arrest (so they know that this is the default intervention), they may be very familiar with how often cardiopulmonary arrest occurs as the final outcome of terminal illness or injury and, through cumulative experience, they may know all too well about the risks and likely outcomes of CPR when it is attempted on terminally ill patients.

There is thus a substantial epistemic gap between patients and clinicians about the realities of hospitalized dying. This epistemic gap exceeds that which is expected to exist between experts and laypeople. In other words, it is not merely because patients are (usually) not trained in medicine that they cannot know about or understand death and dying in the clinical context; clinicians are simply better epistemically positioned to know what these processes entail. However, it is not clear that clinicians' unique knowledge gets effectively relayed to patients or laypeople generally. In the second chapter of *Being Mortal*, Gawande discusses how ill-equipped clinicians are to have difficult conversations about dying with their patients, let alone with the broader lay public. Despite having technical knowledge of the physiological decline terminal patients experience, and empirical knowledge about how harmful aggressive interventions can be in a patient's final days, clinicians may still fail to relay this knowledge for a variety of reasons:

> You'd think doctors would be well equipped to navigate the shoals here, but at least two things get in the way. First, our own views may be unrealistic... Second, we often avoid voicing even these sentiments. Studies find that although doctors usually tell patients when a cancer is not curable, most are reluctant to give a specific prognosis, even when pressed... In an era in which the relationship between patient and doctor is increasingly miscast in retail terms—"the customer is always right"—doctors are especially hesitant to trample on a patient's expectations. You worry far more about being overly pessimistic than you do about being overly optimistic. And talking about dying is enormously fraught. (2014, p. 168)

Thinking specifically of in-hospital resuscitation practices, clinicians may be reluctant to share their knowledge about how likely cardiopulmonary arrest will be the final outcome from terminal illness or injury, or about the harms that CPR and other aggressive end-of-life measures may inflict, perhaps because these realities present patients with grim prospects for their final moments in the hospital. Alternatively, perhaps clinicians get caught up in hospital or medical cultures that valorize doing everything possible to 'save the life' and do not then consider the harmful outcomes associated with nonbeneficial CPR as something patients ought to be concerned with. Either way, the fact that CPR is provided in Canadian hospitals even when there is consensus that it will offer no benefit to the patient, indicates that clinicians' knowledge about outcomes and risks of CPR is not being relayed in ways that enable terminally-ill patients or their SDMs to make their own decisions to prevent intervention (Palda et al., 2005; Downar et al., 2015).

This problem may be embedded within regular hospital practices. In their review of American data on in-hospital DNAR discussions, Yuen et al. (2011) identified that clinicians' discussions with patients about DNAR occur too infrequently, are delayed until too late to allow patients or SDMs to participate in decision-making about resuscitation, or provide minimal information with which patients or SDMs can meaningfully make decisions about care. As a result, patients' preferences for resuscitation go unknown or undocumented and some end up being resuscitated against their wishes. In these cases, the patient is harmed by not having their wishes followed, by being kept alive when survival is no longer a benefit to them—harms that undermine patient autonomy—in addition to being harmed by any injuries from CPR or losses of function due to incomplete recovery from cardiopulmonary arrest—harms that violate the principle of non-maleficence. The absent or failed communication of knowledge that would illuminate the circumstances in which DNAR may be valuable to patients only reinforces the epistemic gap between clinicians and laypeople about hospitalized dying. In turn, this epistemic gap contributes to the epistemic inaccessibility of DNAR orders.

Lastly, and perhaps most obviously, patients and SDMs need to know that DNAR *is* an option available to them in order to opt for these orders. Reporting and tracking of DNAR decisions is linked to reporting and tracking of advance care planning more generally, and the latter is not systematically tracked by any healthcare system in Canada (Digout et al., 2019). As a result, it is difficult to get a sense of the extent to which laypeople are aware of DNAR options in Canada, and the few studies that have attempted to do so have focused on regional surveying at most. For example, in 2012 a group of physicians surveyed nearly 500 patients receiving routine primary care from family

physician offices in Vancouver, to assess their awareness of, knowledge about, and experiences with DNAR decisions[9] (Robinson et al., 2012). The group found that most respondents (84%) had heard of DNAR as an option and preferred to discuss it with their family physician, but very few (8%) of these respondents had indeed discussed it with a healthcare provider (Robinson et al., 2012). These findings offer a promising picture of general DNAR awareness but, importantly, they do not give an indication of how well patients who are aware of DNAR understand the order or its implications. Futhermore, Robinson et al.'s findings were sampled from a relatively small group of adults who i) have regular access to a primary care physician and ii) live in an urban center where public health initiatives to increase awareness of DNAR/advance care planning reach larger populations. These are important demographic circumstances which affect epistemic DNAR accessibility (and are part of what make up structural DNAR accessibility, as I will discuss in the next section).

While I cannot make any strong conclusions about the level of DNAR awareness amongst Canadians generally, I maintain that it is a key part of the epistemic accessibility of DNAR orders; patients cannot choose what they do not know is available to them. Nor can patients meaningfully choose what they do not understand. Patients must therefore be informed of DNAR orders—what they are, how and when they can be selected, and with whom they can be discussed—in order to apply other necessary knowledge (as outlined above) to achieve adequate understanding of DNAR and choose a DNAR order as an end-of-life care option.

[9] The patients surveyed were aged 40 years or older. Note that the research group used 'DNR' terminology in their surveys and report but their descriptions aligned with what I refer to as 'DNAR' orders (Robinson et al., 2012).

iii. Structural Barriers to DNAR Accessibility

Here I identify some issues of process and infrastructure surrounding DNAR that may impact the structural axis of DNAR accessibility, or the resources and processes with which patients and laypeople can access DNAR orders. These barriers are connected in important ways to the epistemic barriers I have outlined, since patients and laypeople must first *know* about DNAR orders in order to apply them. However, these barriers are distinct in that they may limit the practical validity of the DNAR order regardless of whether the patient has knowledge and understanding about its purpose and value (i.e. as a means of preventing overintervention). As I see it, structural barriers to DNAR accessibility are an important issue of justice in healthcare because they deny patients the opportunity to fully exercise their autonomy and to benefit from the full range of healthcare options that are made formally available through Canadian healthcare laws. Furthermore, when combined with the epistemic barriers I have discussed, any structural barriers make patients more vulnerable to any harms induced by CPR and aggressive life-sustaining measures (which are provided by default in the hospital setting) because they cannot effectively refuse them.

First, the processes for selecting and documenting DNAR decisions, which vary significantly between provincial and territorial healthcare systems, have a significant impact on the extent to which patients and SDMs can communicate their choices for care. In most Canadian jurisdictions, a patient or SDM must complete a form to indicate their decision for DNAR status and particular care preferences (e.g. as part of an advance care order), at which point administrative elements like document length, language, or clarity of option selection can be tremendous barriers to patient choice.

For example, a patient or SDM in Nova Scotia, having read only the official Nova Scotia DNR Form[10], may be under the impression that their only option for a DNAR order is to refuse resuscitation attempts of any kind. They may want a single round of defibrillation to be attempted but no intubation or chest compressions in the event of cardiopulmonary arrest, yet they cannot indicate this preference given the limited options offered on the simplistic Nova Scotia DNR Form, and they may not even know that such specifications are possible if they have not discussed resuscitation measures or end-of-life care in general with a healthcare provider. As was true of Robinson et al.'s (2012) survey of patients in Vancouver, this possible scenario is impacted by accessibility to primary care providers in Nova Scotia.[11] Given that access to primary care providers in NS is limited and largely dependent on other demographic factors, many Nova Scotian residents would not have the opportunity to discuss resuscitation options with a clinician prior to hospitalization for a serious illness which would (in theory) prompt such discussion. As a result, patients who may already be disadvantaged are at greater risk of having their options for end-of-life care limited by factors beyond their control.

By contrast, forms like Alberta's Goals of Care Directive offers a precise, tiered list of detailed options for resuscitation efforts, comfort care, and other medical interventions a patient may want (Alberta Health Services, 2021). The wide range of options are outlined in accessible language to maximise choice for patients while facilitating rapid clinician decision-making in the hospital context. The Directivess have also been made widely available to Albertans through provincial efforts to increase

[10] Available as a PDF form on novascotia.ca/dhw/publications/PFEDH_DNR_form.pdf.
[11] In 2019, nearly 15% of Nova Scotians did not have a regular healthcare provider, and access varied significantly by urban/rural location (Statistics Canada, 2019).

advance care planning (Alberta Health Services, 2021). Not only are the Goals of Care Directivess an example of clear and effective communication of end-of-life care options available to patients, but patients and SDM are increasingly exposed to the document and selection protocol themselves. Something as simple as a precise, detailed, and comprehensible form can make the difference between accessibility and inaccessibility for patients and SDMs when selecting options for resuscitation and other end-of-life interventions.

When these options are selected, the second important structural element is the infrastructure in place for documenting these decisions and accessing them when emergency medical care is required. A patient's DNAR order must be effectively communicated to a patient's healthcare team to prevent the initiation of CPR and other life-sustaining measures when cardiopulmonary arrest occurs. Outside of the hospital, challenges arise because paramedics and first-responders are required by law to initiate CPR for patients in cardiopulmonary arrest and can only be directed otherwise by completed, official DNAR forms specific to that province, within the few minutes available to provide intervention. Patients or SDMs who have completed a DNAR form may not have it readily available in the event of a patient's cardiopulmonary arrest in the home or in a public setting, leaving paramedics with no choice but to provide CPR and attempt to stabilize the patient regardless of the patient's or SDM's preferences. This scenario has prompted some advocacy for DNAR databases[12] from which paramedics and first-responders could quickly access patients' resuscitation orders (if these have been

[12] See Winifred Badaiki's interesting blog post for Impact Ethics on "The Need for Do Not Resuscitate Order Databases in Canada" (2021).

recorded and the patient can be identified), in order to ensure that patients' preferences for intervention are being met outside of a healthcare institution.

The challenges of out-of-hospital access to DNAR records highlight that an important part of structural DNAR accessibility are the means of ensuring that patients' resuscitation decisions have practical validity (i.e. will be enacted when the time comes). Within the hospital, confusion and chaos in emergency or intensive care settings can make communication errors more likely, especially when clinical documentation of DNAR decisions is inaccessible. In-hospital systems that facilitate clear, standardized documentation of resuscitation decisions upon admission or shortly thereafter are needed to ensure that DNAR decisions are implemented promptly when cardiopulmonary arrest occurs.

Finally, if and when there are failures in communication and implementation of DNAR decisions and patients receive CPR against their wishes, patients and SDMs need access to judicial or other regulatory responses that grant validity to their decisions by recognizing that their decisions were disregarded. DNAR decisions become effectively meaningless if clinicians can disregard or override them—at which point patient autonomy and healthcare justice are wholly compromised—without triggering legal or other regulatory responses. This element of structural DNAR accessibility is highly complicated because clinicians' professional obligations to provide care they believe is in the patient's best interest can conflict with patients' rights to refuse treatment, but both are legally binding (Bishop et al., 2010). Furthermore, existing dispute resolution processes for CPR/DNAR conflicts between clinicians and patients/SDMs are limited and generally depend on internal (i.e. hospital or institutional) review (Hawryluck, 2016).

These existing processes may offer only limited resources for patients and SDM to seek recourse in the event that their DNAR orders are disregarded, thereby limiting the validity of the DNAR framework.

At present, it seems that attention towards this aspect of the DNAR framework is growing but has yet to yield robust resources for patients and SDMs in Canada. 'Wrongful life' or 'wrongful prolongation of life' lawsuits are relatively recent legal responses to incidents in which patients are resuscitated despite their documented DNAR decisions, but there is limited data on the outcomes of these suits in Canadian courts and whether they provide patients and SDMs with meaningful recourse[13]. Greater focus seems to be placed on resolving CPR/DNAR disputes that arise from clinicians' unilateral judgments of medical futility (Hawryluck, 2016). Although it is unclear how best to ensure that patients' DNAR orders are granted practical validity via legal or regulatory responses to failed DNAR implementation, I argue that it is a key part of structural DNAR accessibility and one that cannot be overlooked in the broader discourse around end-of-life care. DNAR is not a live and meaningful option if patients cannot have their DNAR decisions supported, respected, and defended by social regulatory systems.

To conclude my discussion of the potential epistemic and structural barriers to DNAR accessibility, I reiterate here that these barriers are problematic because they limit patients' and SDMs' resources for challenging or refusing overintervention. When a

[13] A 2017 article by Paula Span for the New York Times discusses the rise of 'wrongful life' suits in the USA and how these represent an important shift in American medico-legal culture. Span explains that "physicians and hospitals have grown accustomed to the threat of lawsuits when they fail to save a patient's life. Now, some face legal action for failing to let a patient die." Since 2017, some American courts have awarded settlements for 'wrongful life' suits when patients' advance/DNAR orders were disregarded, setting important legal precedents for DNAR as a valid and legally-binding decision in end-of-life care (Span, 2021, NYT).

patient or SDM does not have the necessary knowledge or resources with which to select a DNAR order and have it fulfilled in the event of cardiopulmonary arrest, overintervention (i.e. CPR and other life-sustaining measures that are futile per a patient's/SDM's notion of medical futility) can proceed unhindered. Overintervention proceeds by default because it is mandated by in-hospital resuscitation policies relying on presumed consent. In other words, DNAR is the only obstacle to default overintervention (i.e. default full code intervention) for cardiopulmonary arrest in certain hospitalized patients, but it is inaccessible when epistemic or structural barriers limit patients' options for care. At that point, fundamental healthcare goals of non-maleficence (protection from the harms of CPR), respect for patient autonomy (facilitation of patient's decision-making), and justice (equitable access to care and protection of patient rights to refuse treatment) are compromised.

In this section I have explained that epistemic barriers to DNAR accessibility may exist for patients and SDMs depending on: access to knowledge and understanding about the realities of in-hospital dying and death (which can be limited due to the clinical isolation of these experiences, collective reluctance to confront the topic, and insufficient communication of knowledge between clinicians and laypeople); understanding of default in-hospital resuscitation practices and of the realistic outcomes of CPR; and general awareness of DNAR orders themselves. Structural barriers to DNAR accessibility may exist in the resources available to patients for selecting DNAR orders; the infrastructure for documenting patient resuscitation status and accessing these records in the clinical context; and the processes for pursuing legal or other social regulatory recourse when DNAR orders are not implemented. These epistemic and structural

barriers likely reinforce one another and together limit Canadians' access to DNAR orders.

iv. Some Suggestions for Challenging Overintervention: Improving DNAR Accessibility

In this section I provide a brief overview of some suggestions for improving DNAR accessibility and, in turn, challenging the medical and hospital cultural norms that encourage overintervention in end-of-life care. I provide possible solutions to specifically address the barriers to DNAR accessibility I outlined above, drawing from suggestions made by other commentaries in the discourse around CPR/DNAR.

First, epistemic barriers to DNAR accessibility could be significantly minimized by greater communication and education about the realities of in-hospital dying and death. While this will require a shift in collective social habits around confronting the topics of mortality and physiological decline, such a shift could be led and encouraged by healthcare providers who, as I discussed, have unique and intimate knowledge of these biological experiences from witnessing them in the clinical context. Simple changes in clinical practice, paired with improvements in broader public education measures, may greatly improve lay public understanding about hospitalized death from terminal illness, clinical responses to cardiopulmonary arrest, and DNAR and other care orders that are available to patients. Several commentaries have urged for clinical practice to integrate routine discussions between clinicians, patients, and SDMs about resuscitation, its risks and outcomes, and whether it is appropriate at certain stages of illness (Rodriguez & Young, 2005; Bishop et al., 2010; Hawryluck et al., 2016). Ideally, routine informed consent conversations when patients are admitted to hospital, at regular check-ups and medical appointments, and as part of ongoing discussions prior to surgeries or other

procedures, will eventually result in the elimination of any notions of presumed consent to CPR (Boozang, 1993).

As part of these discussions and broader education initiatives, patients and laypeople generally must be informed about the specific risks of CPR and about the ways in which prognosis can change as a result of cardiopulmonary arrest and CPR attempts (Bishop et al., 2010). These details, however grim, are necessary for correcting common misconceptions about CPR success and the preventability of death more broadly, thereby fostering genuine understanding about the "help-hurt line" in end-of-life care (Hawryluck et al., 2016). I argue that such understanding will better equip patients and SDMs to make their own judgments of medical futility on which to base decisions about resuscitation, as well as providing a shared epistemic 'ground' on which patients, SDMs, and clinicians can collaborate in ensuring that healthcare goals of beneficence and non-maleficence are met. As medical practice is increasingly patient-centered, patients' "capacity for autonomous inquiry" into the most appropriate end-of-life care measures must be supported by experts (i.e. clinicians) who can contribute their specific knowledge to patients' process of inquiry, thereby facilitating patients' roles as knowers (Kukla, 2007, p. 30). As a matter of justice and to protect patient autonomy, clinicians have an epistemic responsibility to relay their knowledge about in-hospital cardiopulmonary arrest and CPR to patients and SDMs with which they can apply the medical futility concept. Otherwise, a patient's or SDM's decision-making capacity is at risk of being overridden by the mechanisms of default hospital resuscitation policies.

As many commentaries have pointed out, it is most important that these discussions are initiated *early* (Cotler, 2000; Bishop et al., 2010; Hawryluck et al., 2016).

Clinicians should not wait until terminally ill patients are days or hours from death to initiate dialogue about resuscitation and care preferences; patients and SDMs must be informed of end-of-life realities well in advance in order to maximize their decision-making capacity and promote patient autonomy. As is the case for advance care planning generally, measures to increase and normalize these early discussions will require systemic and policy changes within provincial and territorial healthcare systems. Alberta's Goals of Care initiative provides a good example of such measures; it includes public campaigns encouraging every Albertan aged 18 years or older to have a personal order and designated power of attorney, as well as workplace prompts for healthcare providers to initiate dialogue about Goals of Care Orders with patients as they are admitted to a hospital or healthcare facility, before surgery, at annual check-ups with family physicians, etc. (Alberta Health Services, 2021). These measures achieve a dual purpose of encouraging dialogue about dying and end-of-life care as well as increasing awareness of DNAR orders.

When it comes to addressing structural barriers to DNAR accessibility, I agree with Bishop et al. (2010) that "policy change cannot change culture, but rather that cultural change can lead to policy change" (p. 65). As dialogue about CPR/DNAR becomes increasingly prioritized and encouraged, my sense is that system and policy changes will follow to better support uptake of DNAR orders and advance care planning. For example, as opportunities for informed consent discussions around CPR become more routine, the current default full code system could be changed to something like a default care order system where patients are required upon hospital admission to

complete a care order that includes choices about resuscitation, thereby eliminating any clinical need to rely on presumed consent when cardiopulmonary arrest occurs.

Clear and efficient protocols for DNAR documentation (e.g. standardized forms like Alberta's Goals of Care document; national DNAR databases or DNAR documentation on drivers' licenses, etc.), in-hospital protocols for facilitating DNAR discussions with patients, and enhanced medicolegal infrastructure to support patients' and SDMs' DNAR decisions will, I hope, be achievable system changes once we begin to challenge the institutional presumption of consent to CPR and the broader medical imperatives to fight the inevitability of death. These system changes will of course require initiative from healthcare authorities as well as collaboration between the medical community and the non-medically trained population, but I am optimistic that they are possible.

Finally, there is theoretical work to be done to improve DNAR accessibility and challenge norms of overintervention in end-of-life care. I agree with Schneiderman's (2011) argument that there may be heuristic value in figuring out a clear-cut definition of medical futility which can inform standards of practice and encourage an ethic of care in end-of-life medical decision-making. Schneiderman argues that this project has already resulted in clarity of thinking about end-of-life care (such as distinguishing between medical futility and rationing) and it encourages a more intensive search for evidence-based information about CPR outcomes that medical optimism and default intervention policies currently overshadow (2011). Schneiderman suggests that a clear definition of medical futility will help to hold clinicians accountable to their applications of the

concept (recall from Chapter 2 the concerns about unilateral clinician judgments of futility):

> It is important that we make clear to society as well as to the profession that medicine has great powers, but not unlimited powers. The medical profession has important obligations, but not unlimited obligations. Failing to seek a precise definition of medical futility only leaves us in a state of ambiguity, which encourages the very abuses many people fear. Physicians should not be free to invoke medical futility unless they can justify it before their peers with good evidence-based data and before society with professional standards of practice. This requires that we examine the notion, not hide from it. (2011, p. 126).

I add to Schneiderman's argument that defining medical futility in a way that is meaningful and accessible to patients will enhance their decision-making capacity and promote the sort of understanding of CPR outcomes that contributes to the epistemic accessibility of DNAR orders. I recognize that the project of establishing a clear definition of medical futility does not guarantee that ableism will not play a role in defining the concept (and this should be a significant concern indeed) but I maintain that doing so is an important step in dismantling the "implicit quest for immortality" that may motivate patients, SDMs, and clinicians alike (Bishop et al., 2010, p. 66).

In sum, epistemic and structural barriers, where they exist, limit patients' meaningful and productive access to DNAR orders. This is problematic because it compromises principles of justice and of respect for patient autonomy, by limiting the number of end-of-life care options available to some patients compared to others and by restricting patient choice to the constraints of default action systems (i.e. full code

systems). In practice, barriers to DNAR accessibility make it more likely that patients will receive unwanted or potentially harmful care, given that they do not have the resources with which to refuse it, and may prevent patients from securing a benefit that may be meaningful to them in their final moments of life (e.g. consciousness leading up to shortly before death, ability to speak to loved ones that is prevented by intubation, etc.). In such cases, barriers to DNAR accessibility jeopardize fundamental principles of beneficence and non-maleficence. Finally, practice norms of overintervention can proceed freely when patients and SDMs cannot invoke DNAR for reasons of accessibility because in-hospital resuscitation policies permit and facilitate overintervention on the basis of presumed consent, at which point DNAR orders are the only means for preventing CPR. As such, there is a need for changes to medical culture, system, and policy (like those I have suggested above) with which to improve DNAR accessibility and better support patients, clinicians, and laypeople in challenging the institutional presumption of consent to CPR, honestly confronting the realities of hospitalized dying, and implementing DNAR orders to prevent overintervention and improve quality in end-of-life care.

CHAPTER 4: CONCLUSION

> In the end, we die, and it is not an evil that our biology has made it so. We can and will argue about the timing and the details, about acceptable and unacceptable deaths. That is right and proper. Difficult decisions will never run out. But if we hedge our bets about the inevitability of death, waffling and dreaming—a fresh science-driven embrace of the denial of death—then we are likely to face worse lives and, when it comes, worse deaths. (Callahan, 2005, S8)

In this project, my aim was to critically evaluate the theory, practical value, and accessibility of DNAR orders in the Canadian healthcare context. In the introduction, I first provided an overview of some terminology for resuscitation practices and DNAR orders. I explained how DNAR is a complex framework of medical orders, policies in healthcare, responses in legal discourse, and outcomes for patients, all of which can vary across Canadian healthcare jurisdictions. I also outlined how the DNAR order developed in clinical practice in response to the standardization of CPR and full code measures for in-hospital cardiopulmonary arrest, which contradicted early insights about appropriate use of resuscitation measures. The history of the DNAR order is important for understanding how the bioethical concepts of presumed consent and medical futility have come to shape the modern CPR/DNAR debate. I explored these concepts in depth beginning in Chapter 2.

In Chapter 2, I first examined the concept of presumed consent and its default use in hospital resuscitation policies. I explained how presumed consent to CPR is best understood as an absence of specified refusal or objection to CPR, given that time constraints and the circumstances of in-hospital cardiopulmonary arrest prevent any

opportunity for patients to refuse or object to CPR. In clinical settings, presumed consent to CPR is used by default on the assumptions that cardiopulmonary arrest is an *emergency* and that CPR provides a *benefit to the patient*. I first evaluated the assumption of emergency. Drawing from Bishop et al.'s (2010) distinction between proximal and distal causes, I argued that in-hospital cardiopulmonary arrest, when properly understood as the final outcome of all distal causes, cannot be accurately characterized as an 'emergency' medical crisis. I concluded that the emergency medical protocol structure (which justifies the use of presumed consent) cannot apply for most cases of in-hospital cardiopulmonary arrest given the foreseeability of the medical crisis in terminally ill patients. Secondly, I showed that the empirical evidence on CPR outcomes challenges both premises of the assumption of benefit: that i) CPR is sufficiently beneficial that it outweighs any potential harms, and ii) that the probability of receiving a benefit from CPR is itself significant (i.e. likely). I argued that default use of presumed consent to CPR is inconsistent with empirical facts because CPR must be assumed to provide a benefit in order to justify relying on presumed consent, but CPR is not universally beneficial and is actively harmful in many cases.

Lastly, I briefly examined the use of presumed consent to CPR when bystanders intervene for a stranger in cardiopulmonary arrest in a public setting. I argued that, in such cases, intervening bystanders are acting under epistemic and situational constraints which produce a particular forced choice of action and thus that their default use of presumed consent to CPR may be justified. The emergency public setting provides an interesting contrast case to the default use of presumed consent in the hospital setting because the same constraints are importantly absent in the hospital setting, where

clinicians have greater context for anticipating a hospitalized patient's cardiopulmonary arrest and greater empirical data available on which to assess the possibility of benefit from CPR.

In Section II of Chapter 2, I explored the medical futility concept and its clinical applications in the context of resuscitation and end-of-life care generally. I first provided an overview of technical (quantitative) and qualitative definitions of medical futility and explained some of the conceptual, political, and practical limitations of these definitions. I argued that inconsistent applications of the vague and ill-defined medical futility concept make it epistemically inaccessible and unable to be questioned by those patients subject to them. I argued further that because there is no clear and definitive notion of medical futility by which to consistently and reasonably determine when withholding CPR and invoking DNAR is appropriate, protocols and decisions based on appeals to medical futility (without patient input) are inconsistent and limit the potential for patients and clinicians to reach shared understanding of the concept. Lastly, I described and assessed the ways in which medical futility is applied in current in-hospital resuscitation practices despite the inconsistent theoretical understanding of the concept. I provided an overview of some arguments in support of the concept's use in end-of-life care to foster realistic understanding of the limits of medicine (Bishop et al. 2010), promote patient autonomy and uphold the integrity of the medical profession (Tomlinson & Brody, 1990), and prioritize harm reduction for dying patients (Vivas & Carpenter, 2021).

Having established the theoretical foundation for understanding DNAR orders and their value in the end-of-life care context, I focus in Chapter 3 on clinical practice and policies surrounding CPR/DNAR in Canadian healthcare systems. In the first section, I

outlined the problem of overintervention in end-of-life care (which is related to broader norms of overintervention in current medical practice). Drawing from insights by Atul Gawande and Daniel Callahan, I defined medical overintervention and then provided examples of how it persists in end-of-life care in Canadian hospitals. I argued that overintervention is qualified according to some notion of medical futility, while default use of presumed consent facilitates overintervention in end-of-life care specifically.

Next, I explained how DNAR orders provide patients and SDMs with a resource for resisting and refusing overintervention in end-of-life care, and that this resource is limited if and where patients and laypeople cannot access DNAR orders. To support this point, I identified potential epistemic and structural barriers to DNAR accessibility that may leave Canadian patients and laypeople poorly situated, epistemically- and practically-speaking, to refuse overintervention in end-of-life care. I theorized that epistemic barriers can arise in lay public access to knowledge and understanding about the realities of in-hospital dying and death, understanding of default in-hospital resuscitation practices and of the realistic outcomes of CPR, and general awareness of DNAR orders as a healthcare option. Furthermore, structural barriers to DNAR accessibility may exist in the resources available to patients for selecting DNAR orders, the infrastructure for documenting and accessing DNAR orders and other care decisions, and the processes for pursuing legal or other recourse when DNAR orders are not implemented. DNAR accessibility is limited if and where these barriers exist, thereby reducing patients' and SDMs' resources for enacting their autonomy, securing available healthcare options, and preventing harmful overintervention in end-of-life care.

Finally, I concluded Chapter 3 with an overview of some potential solutions for minimizing the barriers to DNAR accessibility in order to support patients, SDMs, and clinicians in preventing overintervention. I suggested that incremental changes in hospital and medical cultures, as well as improvements in lay public understanding of the limits of medicine and of the biological inevitability of death, would eventually drive policy changes and hopefully result in improvements to the DNAR framework.

In order to uphold the principles of beneficence, non-maleficence, justice, and respect for patient autonomy in the end-of-life care context, patients, SDMs, and clinicians alike must be supported in reaching shared understanding of the purpose and appropriate use of particular medical interventions. The DNAR order is an important resource with which to make clear when CPR is inappropriate—per some understanding of medical futility—and therefore unnecessary and preventable. A theoretical understanding of the DNAR order, including an understanding of its role in addressing and curtailing the medical excesses engendered by presumed consent in the clinical context, is helpful for reminding us of the limits of medicine and the error in denying the biological inevitability of death. It is my hope that, by being mindful of these facts, we can continue to improve end-of-life care in order to facilitate maximal choice and welfare for patients as they seek quietude in death.

REFERENCES

Advance care planning. (2019). HealthLink BC. Accessed 25 June, 2021, from https://www.healthlinkbc.ca/health-feature/advance-care-planning

Advance care planning/goals of care. Alberta Health Services. Retrieved 25 June, 2021, from https://www.albertahealthservices.ca/info/Page9099.aspx

Badaiki, W. (2021). The need for do not order resuscitate order databases in Canada. *Impact Ethics*. Retrieved 05 October, 2021, from https://impactethics.ca/2021/06/16/the-need-for-do-not-resuscitate-order-databases-in-canada/.

Bagheri, A. (2008). Regulating medical futility: Neither excessive patient's autonomy nor physician's paternalism. *European Journal of Health Law*, *15*(1), 45-53. doi.org/10.1163/092902708X300181.

Beauchamp, T. L., & Childress, J. F. (2001). Principles of Biomedical Ethics, 5th ed. New York: Oxford University Press.

Beauchamp, T. L., & Childress, J. F. (2009). Principles of Biomedical Ethics, 6th ed. New York: Oxford University Press.

Bishop, J. P., Brothers, K. B., Perry J. E., Ahmad, A. (2010). Reviving the conversation around CPR/DNR. *The American Journal of Bioethics, 10*(1), 61-67. doi.org/10.1080/15265160903469328

Bjorklund, P., & Lund, D. M. (2019). Informed consent and the aftermath of cardiopulmonary resuscitation: Ethical considerations. *Nursing Ethics, 26*(1), 84-95. doi.org/10.1177/0969733017700234.

Boozang, K. M. (1993). Death wish: Resuscitating self-determination for the critically ill. *Arizona Law Review, 35*(1), 23-85.

Breault, J. L. (2011). DNR, DNAR, or AND? Is language important? *The Oschner Journal, 11*(4), 302-306.

Burns, J. P., Edwards, J., Johnson, J., Cassem, N. H., & Truog, R. D. (2003). Do-not-resuscitate order after 25 years. *Critical Care Medicine, 31*(5), 1543-1550.

Callahan, D. (2005). Death: The distinguished thing. *The Hastings Center Report, 35*(6), S5-S8. doi.org/10.1353/hcr.2005.0090.

Cheon, S., Agarwal, A., Popvic, M., Milakovic, M., Lam, M., Fu, W., DiGiovanni, J., Lam, H., Lechner, B., Pulenzas, N., et al. (2016). The accuracy of clinicians' predictions of survival in advanced cancer: A review. *Annals of Palliative Medicine, 5*(1), 22-29. doi.org/10.3978/j.issn.2224-5820.2015.08.04.

Choose Wisely Canada. Retrieved 05 October, 2021, from https://choosingwiselycanada.org/.

Code status level. (2018). Thunder Bay Regional Health Sciences Center. Retrieved 25 June, 2021, from https://tbrhsc.net/home/caring-for-patients-families/code-status-level/.

Cotler, M. P. (2000). The "Do Not Resuscitate" order; clinical and ethical rationale and implications. *Medicine and Law*, *19*(3), 623-633.

d'Amours, L., Negreanu, D., Briard, J. N., de Champlain, F., & Homier, V. (2020). Assessment of Canadian public automated external defibrillator registries. *CJC Open, 3,* 504-509. doi.org/10.1016/j.cjco.2020.12.013.

Digout, C., Lawson, B., Mackenzie, A., & Burge, F. (2019). Prevalence of having advance orders and a signed power of attorney in Nova Scotia. *Journal of Palliative Care, 34*(3). doi.org/10.1177/0825859719831312.

Downar, J., You, J. J., Bagshaw, S. M., Golan, E., Lamontagne, F., Burns, K., Sridhar, S. K., Seely, A., Meade, M. O., Fox-Robichaud, A. (2015). Nonbeneficial treatment Canada: Definitions, causes, and potential solutions from the perspective of healthcare practitioners. *Critical Care Medicine Journal*, *43*(2), 270-281. doi.org/10.1097/CCM.0000000000000704.

Ebell, M. H., & Afonso, A. M. (2011). Pre-arrest predictors of failure to survive after in-hospital cardiopulmonary resuscitation: a meta-analysis. *Family Practice, 28*(5), 505-515.

Ebell, M., & Herzstein, J. (2015). Improving quality by doing less: Overscreening. *American Family Physician, 91*(1), 23-24.

Ebell, M., & Herzstein, J. (2015). Improving quality by doing less: Overdiagnosis. *American Family Physician, 91*(3), 162-163.

Ebell, M. H., Woncheol, J., Shen, Ye., Geocadin, R. G. (2013). Development and validation of the Good Outcome Following Attempted Resuscitation (GO-FAR) Score to predict neurologically intact survival after in-hospital cardiopulmonary resuscitation. *Journal of American Medical Association, 173*(20), 1872-1878.

Fins, J. J. (2020). Resuscitating patient rights during the pandemic: COVID-19 and the risk of resurgent paternalism. *Cambridge Quartlery of Healthcare Ethics, 30*(2), 215-221. doi.org/10.1017/S0963180120000535.

Freud, S., Hubback, C. J. M., & Sigmund Freud Collection (Library of Congress). (1922). Beyond the pleasure principle.

Gawande, A. (2014). Being mortal : Medicine and what matters in the end. New York: Metropolitan Books, Henry Holt and Co. Print.

Hawryluck, L., Oczkowski, S. J. W., & Handelman, H. (2016). "Must do CPR??": Strategies to cope with the new college of physicians and surgeons of Ontario policy on end-of-life care. *Canadian Journal of Anaesthesia,* 63, 973-980. doi.org/10.1007/s12630-016-0665-3.

Hayek, S. S., Brenner, S. K., Azam, T. U., Shadid, H. R., Anderson, E., Berlin, H., Pan, M., Meloche, C. Feroz, R., O'Hayer, P., et al. (2020). In-hospital cardiac arrest in critically ill patients with covid-19: multicenter cohort study. *BMJ, 371*(m3513). doi.org/10.1136/bmj.m3513.

Health Care Consent Act, 1996, S.O. 1996, c. 2, s. A. Retrieved 25 October, 2021, from https://www.ontario.ca/laws/statute/96h02.

Henry, B. (2016). A reason for the demise of the "Do Not Resuscitate" order. *Annals of Palliative Medicine, 5*(4), 303-307. doi.org/10.21037/apm.2016.09.02.

Herzstein, J. & Ebell, M. (2015). Improving quality by doing less: Overtreatment. *American Family Physician, 91*(5), 289-291.

Janz, H. L. (2019). Ableism: the undiagnosed malady afflicting medicine. *Canadian Medical Association Journal, 191*(17), E478-E479. doi.org/10.1503/cmaj.180903.

Jude, J., & Elam, J. (1965). Fundamentals of Cardiopulmonary Resuscitation. Philadelphia: F.A. Davis Co. Print.

Kidd, A. C., Honney, K., Myint P. K., Holland, R., Bowker, L. K. (2014). Does medical futility matter in 'Do Not Attempt CPR' decision-making?" *International Journal of Clinical Practice*, 68(10), 1190-1192. doi.org/10.1111/ijcp.12476.

Kothari, S., & Kirschner, K. L. (2006). Abandoning the Golden Rule: the problem with "putting ourselves in the patient's place. *Topics in Stroke Rehabilitation, 13*(4), 68-73. doi.org/10.1310/tsr1304-68.

Kukla, Q. (2007). How do patients know? *Hastings Center Report*, *37*(5), 27-35.

Leading Causes of Death, Total Population, by Age Group. (2020). Statistics Canada. Retrieved 25 June, 2021, from https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1310039401.

Options and decision-making at end of life. *(*2017, May 31). Health Services Canada. Retrieved 16 June, 2021, from https://www.canada.ca/en/health-canada/services/options-decision-making-end-life.html.

Palda, V. A., Bowman, K. W., McLean, R. F., & Chapman, M. G. (2005). "Futile" care: Do we provide it? Why? A semistructured, Canada-wide survey of intensive care unit doctors and nurses. *Journal of Critical Care*, *20*(3), 207-213. doi.org/10.1016/j.jcrc.2005.05.006.

Pierscionek, B. K. (2008). What is presumed when we presume consent? *BMC Medical Ethics,* 9(8). doi.org/10.1186/1472-6939-9-8.

Primary health care providers, 2019. (2020). Statistics Canada, 2020. Retrieved 25 June, 2021 from https://www150.statcan.gc.ca/n1/pub/82-625 x/2020001/article/00004-eng.htm.

Providing quality end-of-life care. (2021, March). Canadian Medical Protective Association. Retrieved 25 June, 2021, from https://www.cmpa-acpm.ca/en/advice-publications/browse-articles/2011/end-of-life-care-support-comfort-and-challenging-decisions#:~:text=In%20all%20Canadian%20jurisdictions%2C%20treatment,to%20write%20a%20DNR%20order.

Puri, V. (2006). DNR policies in North America: A procedural morass - resuscitation practices revisited. *Indian Journal of Critical Care Medicine*, *10*(1), 35-39.

Robinson, C., Kolesar, S., Boyko, M., Berkowitz, J., Calam, B, Collins, M. Awareness of Do-Not-Resuscitate orders. *Canadian Family Physician, 58*(4), e229-233.

Rodriguez, K. L. (2006). Perceptions of patients on the utility or futility of end-of-life treatment. *Journal of Medical Ethics,* 32(8), 444-449. dx.doi.org/10.1136/jme.2005.014118.

Rosoff, P., & Schneiderman, L. (2017). Irrational exuberance: Cardiopulmonary resuscitation as fetish. *The American Journal of Bioethics, 17*(2), 26-34. doi.org/10.1080/15265161.2016.1265163.

Ross, J. W. (1991). Judgments of futility: What should ethics committees be thinking about? *HEC Forum,* 3, 201-210.

Schneiderman, L. J. (2011). Defining medical futility and improving medical care. *Bioethical Inquiry, 8,* 123-131. doi.org/10.1007/s11673-011-9293-3.

Siwek, J. (2015). Getting medicine right: Overcoming the problem of overscreening, overdiagnosis, and overtreatment. *American Family Physician, 91*(1), 18-20.

Slosar, J. P. (2007). Medical futility in the post-modern context. *HEC Forum, 19*(1), 67-82. doi.org/10.1007/s10730-007-9028-3.

Span, P. (2017, April 10). The patients were saved. That's why the families are suing. *The New York Times*. https://www.nytimes.com/2017/04/10/health/wrongful-life-lawsuit-dnr.html.

Span, P. (2021, January 22). Filing suit for 'wrongful life'. *The New York Times*. https://www.nytimes.com/2021/01/22/health/elderly-dnr-death-lawsuit.html.

Stapleton, R. D., Ehlenbach, W. J., Deyo, R. A., & Curtis, J. R. (2014). Long-term outcomes after in-hospital CPR in older adults with chronic illness. *Chest*, *146*(5), 1214-1225. doi.org/10.1378/chest.13-2110.

Tomlinson, T., & Brody, H. (1990). Futility and the ethics of resuscitation. *Journal of the American Medical Association, 264*(10), 1990, 1276-1280. doi.org/10.1001/jama.1990.03450100066027.

van Gijn, M. S., Frijns, D., van de Glind, E. M. M., van Munster, B. C., & Hamaker, M. E. (2014). The chance of survival and the functional outcome after in-hospital cardiopulmonary resuscitation in older people: A systematic review. *Age and Ageing, 43*(4), 456-463. doi.org/10.1093/ageing/afu035.

Vivas, L. & Carpenter, T. (2021). Meaningful futility: Requests for resuscitation against medical recommendation. *Journal of Medical Ethics, 47*(10), 654-656. doi.org/10.1136/medethics-2020-106232.

Wawrzyniak v. Livingstone. ONSC 4900. Ontario Supreme Court of Justice. 2019. *Ontario Supreme Court of Justice*. Web. Retrieved 25 June, 2021.

What we heard report. A Public consultation on medical assistance in dying (MAiD). 2020. Government of Canada. Retrieved 25 October, 2021, from https://www.justice.gc.ca/eng/cj-jp/ad-am/glos.html#shr-pg0.

Welbourn, C., & Efstathiou, N. (2018). How does the length of cardiopulmonary resuscitation affect brain damage in patients surviving cardiac arrest? A systematic preview. *Scandinavian Journal of Trauma, Resuscitation and Emergency Medicine, 26*(77). doi.org/10.1186/s13049-018-0476-3.

Wilson, D. M., Houttekier, D., Kunju, S. A., Birch, S., Cohen, J., MacLoed, R., Hewitt, J. A. (2013). A population-based study on advance order completion and completion intention among citizens of the western Canadian province of Alberta. *Journal of Palliative Care, 29*(1), 5-12. doi.org/10.1177/082585971302900102.

Withholding and withdrawal of potentially life-sustaining treatment. Health Law Institute, Dalhousie University. Retrieved 25 June, 2021, from http://eol.law.dal.ca/?page_id=366.

You, J. J., Jayaraman, D., Swinton, M., Jiang, X., & Heyland, D. K. (2019). Supporting shared decision-making about cardiopulmonary resuscitation using a video-based decision-support intervention in a hospital setting: A multisite before–after pilot study. *Canadian Medical Association Journal, 7*(4), E630-E637. doi.org/10.9778/cmajo.20190022.